

# A Comprehensive Approach

PREVENTING BLOOD-BORNE

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INFECTIONS AMONG

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INJECTION DRUG USERS

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The Academy for Educational Development, founded in 1961, is an independent, non-profit organization committed to solving critical social problems in the U.S. and throughout the world through education, social marketing, research, training, policy analysis, and innovative program design and management. Major areas of focus include health, education, youth development, and the environment.

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# Foreword

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*Injection drug users (IDUs) play a key role in the continuing epidemics of HIV and other blood-borne infections, primarily viral hepatitis. Addressing the role that IDUs play in these epidemics is a challenge because it necessitates coordinated action on two of our most complex public health problems—AIDS and drug addiction.*

*In the past, prevention planners, public health agencies, community organizations, and providers tended to focus on one aspect or another of the problem: improving the quality of substance abuse treatment, encouraging HIV prevention education efforts, or helping IDUs who continue to inject to obtain sterile syringes.*

***Preventing Blood-borne Infections Among Injection Drug Users: A Comprehensive Approach** takes a different tack, one that many in the prevention arena recognize and are acting on. No one provider or approach can do it all. To help IDUs reduce their sexual and drug-use risks of transmission, communities and organizations must embrace a broad approach that incorporates a variety of pragmatic strategies addressing IDUs' differing life circumstances, cultures and languages, behaviors, and readiness to change. This technical assistance document describes eight complementary strategies that, together, can make a real difference for HIV prevention for IDUs.*

*Services and interventions for IDUs don't take place in a vacuum, however. They are carried out within a complex, often contentious social, political, and legal environment. Potential partners in the effort to reduce infection among IDUs may not agree on everything, but they do need to find ways to work together so that a critical mass of IDUs can obtain sufficient, high-quality services. **A Comprehensive Approach** discusses this environment and lays out some principles that can help community groups, agencies, and providers begin—or continue—to collaborate.*

*The challenges are substantial, but so are the rewards, for reducing infections among IDUs will translate into a substantial public health benefit for the whole community. We hope this document will help move the field in that direction by providing new ways of thinking about this problem and about IDUs and by encouraging dialogue, collaboration, and constructive action.*



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# Introduction and Overview

*Since 1981, 733,374 cases of AIDS have been reported to the Centers for Disease Control and Prevention (CDC). In 1999, 46,400 new cases were reported. It is estimated that 650,000 to 900,000 Americans are now living with HIV, and that approximately 40,000 new infections occur each year. Approximately 1 to 1.25 million Americans are chronically infected with hepatitis B virus (HBV), and since 1995, approximately 185,000 new infections have occurred each year. An estimated 2.7 million Americans are chronically infected with hepatitis C (HCV).*

These blood-borne infections are transmitted primarily through two routes—sharing contaminated syringes, needles, and other drug injection equipment, and having unprotected sex with infected individuals. Through both types of risk behaviors, injection drug users (IDUs) are an important factor in the continuing evolution of these epidemics. Women who become infected with HIV through sharing needles or having sex with an infected IDU can also transmit the virus to their babies before or during birth or through breastfeeding.

To address this critical public health issue, program managers and staff, policy makers, HIV prevention community planners, and others in the public health community must focus attention on ways in which they can more effectively reach and influence IDUs and must intensify efforts to develop and carry out prevention and treatment strategies directed to IDUs and their sex partners and children. This technical assistance document is designed to help staff, planners, and policy makers accomplish this goal. It first describes the complex problems facing programs and professionals who work with the issue of preventing blood-borne infections in IDUs and then proposes a comprehensive approach to ameliorating these problems. We recognize that other drugs besides injection drugs are also important in the

transmission of blood-borne infections. However, we focus on injection drugs in this document because of the key role they play in the intersection of addiction and infection and because of the myriad ways in which communities and providers can work with injection drug users to reduce their risk and burden of infection.

The core of the comprehensive approach is a group of pragmatic strategies. These strategies recognize that services and interventions for IDUs must be organized so that prevention and behavior change messages can be delivered and reinforced across various settings, populations, life circumstances, patterns of drug use, and stages of behavior change. Though many kinds of services and interventions can be directed toward IDUs and the issues of drug use and disease, eight strategies are included here. They are:

- substance abuse treatment;
- community outreach;
- interventions to increase access to sterile syringes;
- interventions in the criminal justice system;
- strategies to prevent sexual transmission;
- counseling and testing, partner counseling and referral services, and prevention case management;

- coordinated services for IDUs living with HIV/AIDS; and
- primary drug prevention.

These eight strategies are supported by four cross-cutting principles:

- **Ensure coordination and collaboration.** A coordinated and collaborative approach to serving IDUs, their sex partners, and their children is essential because no one provider or institution can or does deliver all required services. The comprehensive approach outlined in this document requires action by many sectors. Providers must work together, sharing their various expertises and outlooks, recognizing and overcoming their philosophical differences, building on existing relationships, and reaching out to groups with whom they may not have worked before.
- **Ensure coverage, access, and quality.** Programs and interventions will not be effective if they do not reach a critical mass of people who can be helped, if IDUs cannot or will not use them, or if they are of poor quality. If they hope to truly reach and help IDUs, agencies and providers must consider ways to effectively deal with these issues as they plan, deliver, and monitor programs and services.

- **Recognize and overcome stigma.** Many people fear and disapprove of injection drug use and consider IDUs to be bad or weak people whose addiction results from moral failure. IDUs live in an environment of high risk and are frequently ostracized. Many, though not all, are poor

*The comprehensive approach consists of 8 pragmatic strategies supported by 4 cross-cutting principles.*

and live on the margins of society. If IDUs are to be successfully engaged in prevention efforts and if public policy is to move forward, these negative attitudes and misconceptions must be recognized and addressed. Addiction is now known to be a treatable, chronic brain disease. Making this understanding of addiction more generally known and accepted is key to overcoming stigma.

- **Tailor services and programs.** IDUs are tremendously diverse. They have different languages, cultures, sexual orientations, life circumstances, behaviors, and requirements for services. In planning and delivering interventions, programs and providers must take into account the factors that characterize IDUs—who they are, where they are, what they do, what motivates them, and with whom they socialize. Tailoring services and programs and involving IDUs in their planning, implementation, and monitoring will make them more effective.

This document describes in more detail the need for and characteristics of the comprehensive approach. It is divided into three chapters:

**Chapter 1: Injection Drug Users Play a Key Role in the Transmission of HIV and Other Blood-borne Infections.** This chapter provides epidemiologic detail on the importance of injection drug use in the epidemics of HIV and other blood-borne infections and describes the drug use and sexual behaviors that place IDUs at risk of infection.

**Chapter 2: The Legal, Social, and Policy Climate Limits Prevention Options for IDUs.** This chapter describes the context within which prevention programs with IDUs must work—the existing stigmas and biases that characterize many public and provider attitudes toward IDUs, even in the face of current knowledge about the nature of addiction, and the policy, legal, and service provision climate that has emerged from these attitudes.

**Chapter 3: A Comprehensive Approach is a More Effective Approach.** This chapter briefly describes the component strategies and principles of the comprehensive approach. Vignettes about selected programs are included throughout this chapter to illustrate the ways in which the strategies and principles are being applied in diverse communities and settings.

This document also includes two **Appendixes**. Appendix A provides greater detail on each of the eight key strategies, including findings from programs and research and discussions of issues and barriers faced by agencies and providers in each of these areas. Appendix B is a matrix of the many research studies and reports cited in Appendix A, organized by strategy so that readers have easy access to this rich literature.

More effective and comprehensive prevention approaches for IDUs will clearly benefit injection drug-using men and women and their partners and children. The benefits have important implications for society as a whole as well, for reducing the transmission of HIV and other blood-borne infections in this population means reducing transmission in the broader population. The results will be a smaller impact on and costs for health and social services, reduced crime, and a more productive society. Many individuals, organizations, and agencies have recognized the importance of the issue of HIV and other blood-borne infections among IDUs and are acting in innovative ways to address them. We hope this document provides the vision and impetus for other program staff and policy makers to take the steps necessary to effectively address the prevention and care needs of injection drug users.

*More effective and comprehensive prevention and treatment approaches will clearly benefit IDUs, their partners and children, and society as a whole.*

# Injection Drug Users Play a Key Role in the Transmission of HIV and Other Blood-borne Infections

*Since 1981, 733,374 cases of AIDS have been reported to the CDC (CDC, 1999a). At least 430,441 of these Americans have died. It is estimated that 650,000 to 900,000 Americans are now living with HIV, and that approximately 40,000 new infections occur each year (CDC, 1999b). HIV infection and AIDS is concentrated in large urban areas, primarily along the East and West Coasts, in the south, and in Puerto Rico. In the late 1980s and early 1990s, AIDS incidence increased in all regions of the country, with the most dramatic increases in the South. Since then, incidence has declined in all regions except the South, where it has remained stable (CDC, 1999b). CDC surveillance data show that injection drug use is directly or indirectly associated with about one-third of all AIDS cases (CDC, 1999a).*

Of the 46,400 new cases of AIDS reported in 1999, almost 14,000 were IDU-associated:

- 7,207, or 52 percent of these IDU-associated cases, were heterosexual male IDUs;
- 2,931, or 21 percent, were female IDUs;
- 1,806, or 13 percent, were men who have sex with men and were IDUs;
- 1,790, or 13 percent, were heterosexual sex partners of IDUs; and
- 99, or less than 1 percent, were children whose mothers were IDUs or the sex partners of IDUs.

These numbers for IDU-associated AIDS cases in 1999 are minimum estimates, as 11,209 of the 46,400 cases (24 percent) were classified as “other/risk not reported or identified.” Some of these cases were IDU-associated.

Data from prevalence surveys and case surveillance continue to demonstrate the

heavy impact of the HIV/AIDS epidemic on racial and ethnic minority populations and on women, youth, and children. The data suggest three interrelated issues play a role in this—disparities in socioeconomic status, the nation’s inability to substantially reduce substance abuse, and the intersection of substance abuse and the epidemics of HIV and other STDs. There is no question that drug use plays a major role in the spread of the epidemic of HIV and other blood-borne infections among African Americans and Hispanics, both through the direct impact of injection drug use and indirectly through sex with an IDU or through the exchange of sex for drugs or money (CDC, 1999a; CDC, 1999b). In 1998, IDU-associated AIDS cases represented almost 40 percent of all cases among African Americans and 43 percent of all cases among Hispanics (CDC, 1999b). In 1998, the IDU-associated infection rate was five times higher among Hispanics than among whites and more than ten times higher among African Americans than among whites (CDC, 1999c).

Within these continuing high numbers, however, there appear to be some promising trends. Partly because of prevention efforts targeting those at highest risk, the epidemic has slowed considerably since its earliest days (CDC, 1999b). HIV seroincidence in injection drug users has declined over the past several years in the largest drug-using communities, including New York, northern New Jersey, and Los Angeles (Des Jarlais et al., 2000; Holmberg, 1996). These declines can be attributed to changes in IDUs’ risk behaviors, including greater use of sterile

**Injection drug use is a major force in HIV/AIDS:**

- *about 1/3 of adult AIDS cases are related to injection drug use*

needles, more disinfection of drug preparation equipment, shifts from injection to snorting, and stopping using drugs.

The shift from injecting to snorting drugs is documented by information on drug use trends gathered by the National Institute on Drug Abuse's (NIDA) Community Epidemiology Work Group (CEWG, 1998). CEWG contributors report that although heroin use indicators continue to increase in 12 cities monitored by CEWG, in those cities in which high-purity white powder heroin is available, heroin snorting has become much more prevalent and is spreading to new and younger users. However, this may be a short-lived trend, as many of these snorters may shift to injecting if the purity of available heroin drops. It is also known that many drug users who begin by snorting heroin eventually move to injecting it (Irwin et al., 1996).

The findings on declining seroprevalence have been supported by other recent work, including an examination of temporal trends in HIV seroprevalence in New York from 1991 to 1996 (Des Jarlais et al., 1998). New York has between 170,000 to over 200,000 IDUs and almost 50,000 cases of diagnosed AIDS among IDUs and their partners and children (Des Jarlais et al., 1998). New York City accounts for almost one-fourth of the IDU AIDS cases in the U.S. and almost one-tenth of all AIDS cases in the U.S. During the first half of the 1990s, the city saw a steady decline in HIV seroprevalence. The authors attribute the decline in number of seropositive IDUs to two major factors. The first is the death of many HIV-positive IDUs who became infected early in the epidemic. Others may have become too ill to engage in the activities needed to obtain and use drugs. The second factor is the adoption of risk reduction behaviors as a result of community outreach efforts, syringe exchange programs, and other contributing factors.

The transmission of other blood-borne diseases, primarily hepatitis B and hepatitis C, through unsafe sex and sharing needles, syringes, and drug preparation equipment, such as filters, water, and cookers, is another important concern for public health agencies and service providers. Approximately 1 to 1.25 million Americans are chronically infected with hepatitis B virus (HBV), and since 1995, approximately 185,000 new infections have occurred each year. The CDC reports that the incidence of HBV infection increased through the mid-1980s, then declined through 1994. A small portion of this decline is attributed to the wider use

### IDUs are also important in the hepatitis C epidemic:

- *illegal drug use and high-risk sex are the factors most strongly associated with hepatitis C infection among those 17-59 years old*
- *½ of hepatitis C cases in the U.S. are directly or indirectly linked to illegal drug use*

of vaccine among healthcare workers. It is hypothesized that a significant portion of this decline was the result of reduced high-risk practices following the introduction of HIV prevention messages.

An estimated 2.7 million Americans are chronically infected with hepatitis C. Most are unaware of their infection because some individuals experience no symptoms for 20-30 years after infection (Alter et al.,

1999). However, hepatitis C is a major cause of cirrhosis and liver cancer, and HCV-related end stage liver disease is the leading reason for liver transplantation in the U.S. The estimated annual incidence of hepatitis C remained relatively stable through much of the 1980s. However, based on sentinel surveillance for acute viral hepatitis conducted in four U.S. counties, the CDC estimates that the average number of newly acquired HCV infections has declined from 180,000 in 1984 to 40,000 in 1998 (Alter and Moyer 1998, CDC unpublished data). The risk of exposure to HCV from transfused blood has declined dramatically in recent years with improvements in screening blood donations. In contrast, illegal drug use currently accounts for about 60 percent of HCV transmission, while sexual exposures account for 20 percent (Alter, 1999). Studies have consistently shown that injection drug use is the single most important risk factor for hepatitis C virus infection (Alter et al., 1999; Alter and Moyer, 1998; Garfein et al., 1998; Thomas et al., 1995). Among IDUs, hepatitis C virus infection is extremely prevalent—in studies conducted worldwide, from 50 to 95 percent of IDUs are infected (Garfein et al., 1998). This high prevalence persists even in populations in which the prevalence of HIV is relatively low (van Beek et al., 1998). This may be because HCV has a higher average transmission efficiency than does HIV (Coutinho, 1998; Crofts et al., 2000). In addition, HIV may be transmitted on equipment such as swabs, spoons, and rinse water that may be commonly shared by IDUs even if they do not share syringes<sup>1</sup> (Coutinho, 1998; Crofts et al., 2000). Another reason why HCV is of particular concern is that infection appears to be acquired relatively soon after drug injecting is initiated (one study reported that 50 to 80 percent of new IDUs became infected within 6 to 12 months of first injecting [Garfein et al., 1996]). However, more recent studies are suggesting that IDUs are getting infected at a slower rate (Garfein et

<sup>1</sup>The term "syringe" is used throughout this document to refer to the needle and all other parts of the syringe.

al., 2000). There is however a very large reservoir of potentially infectious individuals, which provides multiple opportunities for transmission to occur (Alter and Moyer, 1998).

### **Risk Behaviors Associated with Infection by HIV and Other Blood-borne Infections**

#### **DRUG PRACTICES**

The process of preparing and injecting drugs and the various items of equipment used provide many opportunities for contamination with and transmission of HIV or other blood-borne viruses (AED, 1997).

To be injected, drugs such as heroin must be dissolved in water. Heat is sometimes used to speed the process. This is typically done in a spoon or a bottle cap, called a “cooker.” The drug and water solution is then drawn into a syringe through a filter or a “cotton,” which prevents small particles in the solution from clogging the narrow gauge needle.

Before injecting intravenously, an IDU must determine whether the needle is in a vein. To do so, he or she pulls back the syringe plunger to see if blood enters the syringe. This is called “registering.” If blood registers, the needle is in a vein. Registering contaminates the entire syringe with blood: needle, hub, barrel, and plunger (Koester, 1998; Normand et al., 1995).

Once the user registers that the needle is in a suitable vein, the drug is injected directly. To ensure that all the drug is injected, the IDU may pull the plunger back several times, drawing blood into the syringe each time, and then re-injecting it. This technique, called “booting,” increases the presence of residual blood in the syringe (Koester, 1998; Normand et al., 1995).

HIV survives in the residual blood in used syringes, even if it has been rinsed with water. A recent study showed that HIV in used syringes remained viable and infectious at room temperature for more than 4 weeks (Abdala, 1999).

After injecting the drug, the IDU rinses the syringe with water to prevent any remaining blood from clotting. This contaminates the rinse water. Drug injection may take place in locations with little access to water, so rinse water may be reused and therefore become increasingly contaminated. In many cases, this water is used for dissolving drugs to be injected as well as for rinsing. In the absence of a sufficient supply of new sterile syringes, IDUs must reuse their syringes. Disinfecting used syringes with bleach is recommended as a risk reduction measure, but even if done correctly, it is not as safe as using a new, sterile syringe. In reality, the multiple steps involved in the bleaching procedure and the difficulty of adequately cleaning the hard-to-reach internal spaces of a syringe mean that many IDUs are unable to properly disinfect their used syringes. (Gershon, 1998; Gleghorn et al., 1994; McCoy et al., 1994).

The patterns of cocaine and heroin use present particular viral transmission risks (Koester et al., 1996). The desire and need for cocaine mean that users of this drug inject frequently, multiplying the opportunities for transmission of blood-borne viruses. Heroin injectors make fewer injections per day, but their risks are multiplied because of their overwhelming physical and emotional need to avoid the withdrawal syndrome. Their objective is to inject as soon as possible after obtaining the drug, which means they may use whatever syringe or equipment is closest to hand, whether or not that presents viral infection transmission risks (Koester et al., 1996).

Transmission of HIV and other blood-borne viruses can occur through either direct or indirect sharing of contaminated equipment. Direct sharing involves injecting drugs with a syringe already used by another injector. Indirect sharing occurs when injectors prepare their own drugs but use injection paraphernalia, such as water, cookers, cottons, and spoons, that others have used, or when injectors jointly prepare and share drugs (Koester and Hoffer, 1994). This occurs,

for example, when several IDUs pool their money to purchase drugs together. The entire amount of drug is dissolved during a shared preparation process. The preparer draws all the drug and water solution into a syringe through the cotton. Using the calibrations on the syringe, the preparer then transfers individual doses of the drug into the syringes of the other users. After injecting the drug, users rinse their syringes with water. Though syringes themselves are not used by more than one person in indirect sharing, they still become contaminated with blood because of contact with contaminated ancillary paraphernalia.

Other practices associated with indirect sharing can also transmit infection, including (Koester and Hoffer, 1994):

- Squirting the drug solution from a previously blood-contaminated syringe into the cooker or spoon and then drawing it into another syringe.
- Using the plunger from a previously blood-contaminated syringe to mix the drug with water.
- Returning the drug solution from a previously blood-contaminated syringe to the shared cooker or directly to another syringe. This occurs when the user draws up more than his or her allotted share of the drug.
- “Beating,” or pressing, a used cotton (or several cottons) to retrieve any drug remaining in the cotton from a previous injecting session.
- “Kicking out a taste” by putting a part of the drug/water solution from a previously blood-contaminated syringe back into the cooker or into another IDU’s syringe so that another or several other IDUs can get some of the drug.
- Drawing up the water for dissolving the drug by using another injector’s used and inadequately disinfected syringe.

Another attribute of drug use that contributes to the risk of viral transmission is

the use of more than one drug. For example, IDUs often use alcohol, cigarettes, and marijuana in addition to the drug they inject (AED, 1997). "Speedball," a combination of heroin and cocaine is favored by some injectors, and has been highly correlated with HIV infection (Battjes et al., 1994). Common reasons for this polydrug use include the need to counteract the effects of one drug with another, the desire to experience the effects of more than one drug, and the need to substitute when the drug of choice is too difficult or costly to obtain. Polydrug use can increase the risk of HIV and other blood-borne disease transmission in several ways. For example, the situations and people with whom an IDU uses drugs may vary depending on the drug. These differing contexts may expose the individual to a variety of high-risk situations. Furthermore, intoxication with one drug may lessen an individual's ability or desire to reduce risks associated with the use of another drug.

*High-risk drug use behaviors and high-risk sexual behaviors are often linked, further increasing risk of transmission.*

## SEXUAL BEHAVIORS

High-risk drug use behaviors and high-risk sexual behaviors are often linked, further increasing the risk of HIV and other blood-borne diseases being transmitted from one person to another (Chu et al., 1998). These risky sexual behaviors include unprotected anal, vaginal, or oral sex; multiple partners; and lack of treatment of sexually transmitted diseases (STDs), especially those with

ulcerative lesions. These high-risk drug and sexual behaviors intersect in a variety of ways to increase risk. For example, sex partners of HIV-infected IDUs may begin injecting drugs themselves (Ouellet et al., 1998). Drug injectors who also frequently smoke crack cocaine tend to spend time in crack houses or other places with other drug-injecting cocaine users (Friedman et al., 1995). Crack use is associated with high-risk sexual activities, possibly because of the disinhibiting effect of the drug or because of the addicted person's need to obtain the drug, which leads to exchanges of sex for crack or for money to buy crack (Edlin et al., 1994). Many IDUs, both men and women, trade sex for drugs or money to buy drugs or engage in commercial sex or hustling to generate income for their habits and this increases their transmission risks (AED, 1997; Kail et al., 1995; Rietmeijer et al., 1998; Schilling et al., 1992).

### **The Context of High-risk Drug and Sexual Practices**

The degree of risk associated with injecting drugs is determined in part by the physical setting in which it takes place and the people with whom a user injects. An understanding of the contexts in which drug use occurs is particularly important because they help to explain the ways drug use takes place and they help define individual users and the other people with whom they spend time, buy drugs, inject drugs, and have sex. This knowledge, in turn, illuminates the ways in which infection is transmitted from one individual to another, as well as from small high-seroprevalence groups to the larger community (Des Jarlais et al., 1993; Friedman et al., 1995; Friedman et al., 1997; Needle et al., 1995). Armed with these insights, policy makers and service providers can develop prevention interventions that are tailored to the characteristics and needs of specific groups of injection drug users (AED, 1997; Bourgois, 1998; IOM, 1995). The following sections discuss several key social contexts for drug use.

## DRUG USE SETTINGS

Drug use takes place in a variety of locations that allow people to inject by themselves or in small groups. These locations include apartments or homes, bars, massage parlors, social clubs, residential hotels, abandoned buildings, public bathrooms, and "shooting galleries" (AED, 1997; Des Jarlais et al., 1993; IOM, 1995; Latkin et al., 1996a). In some settings, users rent out needles and other equipment for a small fee or a portion of the user's drug, which is paid to the dealer operating the gallery. The needles are then returned and used by the next injector. In other settings, sharing drugs or equipment occurs without payment of drugs or money. Key components of this context are the number of drug users in the setting and the riskiness of the behaviors. When a setting brings together multiple individuals who prepare and inject drugs in risky ways (with few syringes and widespread direct and indirect sharing) or who have high-risk sex, transmission of HIV and other blood-borne viruses can spread rapidly and efficiently from one user to others (Latkin et al., 1994).

## SOCIAL NETWORKS

These are groups of users linked by various relationships and bonds. Networks differ based on the number of members and how stable the relationships are, the types of relationships among members, the degree to which the group is open to including new members, the kind of social activity that occurs within it, and the types of drug used and how they are used (Friedman et al., 1997; Needle et al., 1995). In addition, networks may be defined by race or ethnicity, gender, sexual orientation, social class, and the presence of kinship among members.

The nature of the relationships among members and the interpersonal and group dynamics of the network directly affects a member's drug-use and sexual behaviors and therefore are highly influential in determining that person's risk of infection (Friedman

et al., 1997; Latkin et al., 1996b; Needle et al., 1995). For example, some networks are small, consisting of a close group of drug-using or sex partners. These individuals may have increased risk because they may be less likely to use condoms or sterile syringes, which may conflict with the intimacy and trust developed in the relationships. Other types of networks are characterized by a larger, more open membership, and the level of risky behavior engaged in by members is influenced by the settings in which drug use takes place and the closeness of the ties that bind members (Trotter, 1995). A member who has close links with other drug injectors in the network is more likely to engage in high-risk practices, such as sharing syringes or injecting in shooting galleries, than are drug injectors who are only peripherally connected to other network members (Friedman et al., 1997). Furthermore, those members with the most material resources are at the top of the network's hierarchy. When sharing drugs, they will shoot first, which may make it more likely that they will use a sterile syringe and equipment. In contrast, the newest members of the network or those with the fewest material and other resources command the least respect and exist on the margins of the network. They often must engage in the riskiest drug and equipment sharing practices, such as collecting used cottons to extract any drug remaining in them (Bourgois, 1998; Bourgois, unpublished).

Social networks are a critically important context for understanding drug use and its intersection with the transmission of HIV and other blood-borne pathogens because of their role in maintaining an epidemic within the group and in providing a starting point for rapid transmission beyond the group (Friedman et al., 1997). They are also a critically important context when considering prevention efforts because these same dynamics also may be used to introduce and reinforce norms that support risk reduction and to develop effective channels of communication with members (Latkin, 1995).

### MEMBERSHIP IN GROUPS WITH ESPECIALLY HIGH RISKS

Certain groups of injection drug users warrant particular attention because their occupations or behaviors lead to drug- and sexually-related transmission risks that appear to be higher than they are for other populations. They can experience considerable societal stigma to begin with because of these occupations and behaviors, and their drug use compounds this problem and contributes to their higher transmission risk. For example, many IDUs have coexisting problems, such as mental illness, physical illness, homelessness, and incarceration. As many as 30 percent of homeless adults may be substance abusers. (NIDA, 1990; Schutt et al., 1992). Overall, homeless adults have higher HIV rates than do the general population, particularly in high prevalence areas. A recent survey of homeless adults using a storefront medical clinic found that more than two-thirds were at risk of HIV infection from various sources, including unprotected sex with multiple partners, injection drug use, sex with an IDU partner, or exchanges of sex for money or drugs (St. Lawrence and Brasfield, 1995). Some homeless also have mental illness and violent and unstable living situations, and because of this they find it difficult to form the safe, intimate relationships that could help them reduce their risk. Limited availability of or access to mental health services increases this problem.

Men and women in prisons and jails also suffer disproportionately high rates of drug abuse as well as of HIV infection. Recent data from the National Center on Addiction and Substance Abuse (CASA) show a direct or indirect connection between substance abuse and the incarceration of nearly 80 percent of those in federal, state, and local prisons and jails (Belenko, 1998); 60-80 percent of inmates have serious substance abuse problems (Leshner, 1999). Another recent report, published by the National Institute of Justice, CDC, and

the Bureau of Justice Statistics shows that in 1996, 24,881 inmates in state and federal prisons were known to be infected with HIV (Hammett et al., 1999). HIV-positive inmates comprised 2.4 percent of the state prison population in 1996 and 1.0 percent of the federal prison population. Between 1991 and 1996, the number of HIV-positive inmates grew at about the same rate as the overall prison population (both increased by about 42 percent).

Female sex workers and female IDUs who have sex with other women are particularly vulnerable to infection because many are poor and homeless and addicted to alcohol as well as drugs. Female IDUs who trade sex for money or drugs are more likely to share needles than are female injectors who do not engage in sex trading, and are less likely to use new needles or to clean old ones (Kail et al., 1995). Female drug-injecting partners of male IDUs may be more likely to inject after the man and therefore be exposed to greater risk.

#### Key contexts of high-risk behaviors:

- *drug use settings*
- *social networks*
- *membership in groups with high risk*
- *geography*
- *income and social factors*

Regardless of the origin of their risks, these women often exist in a subordinate and physically dependent relationship to the men with whom they interact, and these power imbalances make it difficult for them to change their behaviors in ways that might reduce risk (AED, 1997; Bourgois, unpublished).

Young injection drug users are another group who require increased attention because the contexts in which they inject frequently increase their risk of transmission. Young IDUs may be runaways or peripheral members of drug-using social networks. If they lack money to buy drugs, they may be forced to trade sex for drugs or money.

Men who have sex with men (MSM) and inject drugs also face increased risks of transmission. For example, recent evidence from CEWG shows that methamphetamine use, once largely restricted to the West, is now spreading into other parts of the country and gaining in popularity among MSM. Methamphetamines can be administered in several ways but the injection route appears to be increasingly common. This method of administration increases a user's chances for engaging in high-risk sexual and non-sexual behaviors, thus increasing the risk of acquiring or transmitting infection (NIDA, 2000).

#### GEOGRAPHIC DIFFERENCES

Location often influences the types of drugs available, and this in turn dictates the method of administration (e.g., injected, smoked) and the level of risk experienced by users (Sullivan et al., 1998). For example, the two major sources of heroin in the United States today are South America and Mexico. South American heroin is distributed primarily to cities on the East Coast and is a high purity, white powder form of the drug. Because of this high purity (60-70 percent), an increasing number of users are resorting to snorting the drug rather than injecting it (CEWG, 1998). In contrast, the major forms of heroin available on the West Coast, Texas, and some Midwestern cities, such as Chicago and St. Louis, are Mexican black tar and brown powdered

heroin. Mexican black tar heroin also has recently reappeared in Atlanta (CEWG, 1998). Black tar heroin is less pure than the white powder form (39 percent) and has a consistency somewhere between tar and wax. Its difficult texture makes it hard to snort and users are therefore more likely to inject it, which exposes them to the potential transmission risks associated with injection practices. The combination of the texture and the drug's cost (in San Francisco, it is commonly sold in \$20 units about the size of pencil eraser) also increases the chances that IDUs who are short of money will share the drug. This involves dissolving the drug and dividing it into portions equivalent to the money each person contributed to the purchase of the drug. This procedure increases the risk of infection through shared needles and ancillary paraphernalia (Bourgois, unpublished; Koester and Hoffer, 1994).

#### INCOME AND SOCIAL FACTORS

Many IDUs have jobs and health insurance (Eisenhandler and Drucker, 1993; SAMHSA, 1999). Others are less involved in the mainstream economy and must resort to a variety of tactics to support their habits, including panhandling, scavenging, day labor, sex work, and petty theft. As noted already, the relative social status of IDUs has a direct influence on the degree of risky behavior necessary for survival. Those who begin with higher social status and more secure income, housing, and support networks may be more able to control their risks of transmission. Poorer IDUs, those with concomitant health or mental problems, and those with unstable living and social circumstances may have difficulty obtaining sterile syringes or be more susceptible to legal penalties for syringe possession, and thus may be more likely to pursue risky behaviors, such as sharing

injection equipment (Bluthenthal et al., 1999a; Bluthenthal et al., 1999b; Case et al., 1998). For these IDUs, any change in financial or social circumstances can have a significant impact on their risk profile. A case in point is the 1997 federal decision to cease Supplemental Security Income (SSI) benefit payments to individuals whose drug or alcohol addiction is considered a contributing factor to their disability. Data from a 1995 study of IDUs living in six San Francisco area communities showed that benefits for SSI recipients contributed to the overall stability of their lives and to a lower risk of acquiring or transmitting infection because they were less likely to be homeless, were less reliant on illegal income, used drugs less often, and shared syringes less often than did IDUs who did not receive benefits (Lorvick et al., 1997). A follow-up study showed that those who lost SSI benefits as a result of the ruling were more likely to participate in illegal activities, more likely to share syringes, and injected drugs more often than did those who retained benefits (Bluthenthal et al., 1999b).

#### Conclusion

Today, a major force behind the epidemic of HIV and other blood-borne illnesses is infections among IDUs, their sex partners, and their children. IDUs engage in a number of drug-use and sexual practices that significantly increase their risk of contracting HIV and hepatitis and of passing them on to others. The next chapter of this document further describes the problem facing programs and professionals as they address the complex prevention needs of IDUs: the environment of stigma and bias—the “junkiephobia”—in which many IDUs live and the policy, legal, and service provision climate that has emerged from these attitudes.

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# The Legal, Social, and Policy Climate Limits Prevention Options for IDUs

*The AIDS epidemic and the public health importance of other blood-borne illnesses, primarily hepatitis B and hepatitis C, have introduced a new dimension to the issue of injection drug use and increased the urgency of finding effective and appropriate interventions for IDUs. Numerous studies have examined issues related to the nature of addiction, the reasons why individuals begin and continue to use addictive drugs, and the factors that help them change their behaviors so as to stop using drugs. Despite this growing body of scientific knowledge, many myths, negative stereotypes, and biases persist about drug users and their lives, the health and safety risks they take, and their ability to overcome addiction. These stereotypes and beliefs profoundly influence the service, policy, and legal environment affecting IDUs and the scope and quality of health and social services provided to them (Friedman, 1998). They also constrain efforts to reduce the spread of blood-borne pathogens among IDUs and achieve the nation's ultimate goal, which is to substantially reduce or even eliminate drug use. To design and deliver effective interventions for IDUs, prevention providers, program staff, and policy makers must better understand the lives and issues faced by IDUs, address the biases they and society have toward this population, and work to ameliorate the stigma caused by such biases. They must also explore ways to surmount the profound differences in philosophy and approach that exist among various types of providers and that all too often hinder collaboration and limit effective solutions.*

## **Negative Attitudes and Stigma Toward IDUs Persist Despite a New Understanding of Addiction**

Negative attitudes and biases about addiction and drug users are pervasive and derive from experience and deeply felt moral and philosophical beliefs. These attitudes, widespread among the general public and many policy makers, are prevalent even among service providers and health professionals (Cole and Slocumb, 1993; McGrory et al., 1990; Wallack, 1991; Yedidia et al., 1993; Yedidia et al., 1996). IDUs are stigmatized, seen as less valuable citizens than others in the population.

Many IDUs are marginalized, without full participation in the economic, social, or cultural life of their community. For those IDUs who are infected with HIV or other blood-borne illnesses or who have associated mental illness or other conditions, the stigmatization and marginalization are further increased (Des Jarlais et al., 1993).

In the eyes of many, IDUs, at best, are seen as victims of their addiction. At worst, they are viewed as criminals or as weak and bad people whose chaotic lives and inability to overcome addiction result from moral failure rather than from a legitimate medical

condition or a lack of access to adequate, comprehensive treatment (Des Jarlais et al., 1993; Leshner, 1997). They are regarded somehow as alien figures, as one of "them," not one of "us." Their addiction or resulting infection with HIV or hepatitis is "their fault." IDUs are incorrectly perceived to be unwilling to change their behaviors or unable to respond to education, outreach, or treatment interventions (Jones and Anderson, 1999). These negative and dehumanizing attitudes toward IDUs even extend to the providers and programs that work with them. These professionals and organizations are also seen as having lower

social value than those working with mainstream populations and are often stigmatized for serving IDUs (AED, 1999; Friedman, 1998).

“Junkiephobia” is a term that has been used to encapsulate this complex of stereotypes, stigma, and negative attitudes toward IDUs (Jones and Anderson, 1999). Like “racism” and “homophobia,” “junkiephobia” covers a number of social and individual factors underlying these attitudes. For example, a lack of knowledge about addiction and ignorance of the lives and cultures of IDUs is a factor leading to stereotyping and stigmatization. Fear of the addictive capacity of drugs and of addicts themselves is another factor. Reluctance to support policies that might appear to promote or condone drug use, such as syringe exchange, is a third powerful factor. Lack of specific provider training and education also hamper those in service agencies from providing empathetic, responsive, and appropriate services and education to IDUs.

These attitudes persist among the public, policy makers, and service providers despite advances in the neurosciences and the behavioral sciences that have transformed the understanding of drug abuse and addiction. It is now known that the roots of addiction lie in a series of complex biochemical changes that occur in the brain over time, causing alterations in brain function. The result is a chronic and relapsing, but treatable, disease with intertwined biological, behavioral, and social components.

Studies over the last 20 years have revealed that all drugs have the same effects on a single pathway deep inside the brain, the mesolimbic dopamine system (Childress et al., 1999; Koob, 1996; Koob, 1992; NIDA/Hospital Practice, 1997; Volkow et al., 1993). When activated in response to natural rewards, such as food, water, sex, and nurturing, this pathway provides pleasurable feelings. These pleasurable feelings cause the individual to repeat the behavior to reactivate the reward pathway. All addictive drugs,

including heroin, cocaine, marijuana, alcohol, and nicotine, also activate this reward system by causing an extra release of dopamine into the pathway. Initially, an individual uses a drug because of the pleasurable effects on mood, perception, and psychological state. Prolonged drug use, however, causes fundamental and long-lasting changes in the brain. At some point, these changes throw a metaphorical “switch” in the brain. Once the switch is thrown, the individual moves from a state of voluntary drug use to a state of addiction in which drug seeking and use are uncontrollable and compulsive. In the addicted state, the pleasurable effects of the drug may be minimized or absent altogether.

The compulsion to use some drugs, like

*Addiction is no longer defined so much by the element of physical dependence, but is increasingly described as compulsive drug seeking and use that come to dominate a drug addict's life, even in the face of terrible physical and social consequences.*

heroin, is partly driven by the need to ward off the withdrawal syndrome, which occurs when use is stopped or reduced. This syndrome is characterized by nausea and vomiting, muscle cramps, sweating, agitation, and depression. Because these symptoms can be managed with medications and because not all addictive drugs result in this syndrome (cocaine, for example, does not), addiction is no longer defined so much by the element of physical dependence, but is increasingly described as compulsive drug seeking and use that come to dominate a drug addict's life, even in the face of terrible

physical and social consequences (Leshner, 1997; NIH, 1997).

Another concept that is key to the current understanding of drug addiction is that it is not an acute illness, but rather a chronic, relapsing condition that is treatable. Like other chronic illnesses, such as diabetes, asthma, or hypertension, appropriate treatment must be focused more on effective management over the long term rather

*Overall, treatment for addiction is as successful as treatment of other chronic conditions, such as asthma, diabetes, and hypertension.*

than on a permanent cure (Leshner, 1997). Treatment compliance and relapse rates in drug addiction are about the same as in these other chronic medical conditions (O'Brien and McLellan, 1996).

### **Negative Attitudes Toward IDUs Affect Public Policy and Treatment Approaches**

Public and provider attitudes and perceptions about drug use and users color attitudes toward appropriate responses to the problem of injection drug use. The substantial investment in prisons and criminal justice institutions, the relatively limited public support for substance abuse treatment, and laws and regulations limiting sterile syringe sales and syringe exchange programs appear to reflect a national inclination to respond to drug users in a punitive and dehumanizing fashion. For example, active drug users are disqualified from the federal Supplemental Security Income program if their addiction is considered to be a contributing factor to their disability (Bluthenthal et al., 1999; Lorvick et al., 1999), and welfare recipients are tested for

drug use and may lose their benefits if the test is positive (though in some areas they may retain food and rent vouchers) (Friedman, 1998). Pregnant drug-using women still face barriers in obtaining treatment and, should they be incarcerated, in obtaining prenatal care and retaining custody of their child after delivery (Breitbart et al., 1994; GAO, 1999).

The impact of these public and personal attitudes on current laws, regulations, and policies can be seen in several ways:

◆ **Emphasis on criminal penalties rather than treatment.** With several notable exceptions (alcohol and tobacco use by adults), the use of addictive drugs is illegal

**Legal and public policy results of attitudes and stigma:**

- *emphasis on criminal punishment over treatment*
- *differences in funding priorities*
- *limited drug treatment services*
- *restrictive syringe prescription and paraphernalia laws and regulations*
- *a fragmented and polarized atmosphere*

and users are subject to arrest and incarceration. Punitive laws for drug possession and dealing channel users and IDUs into prison rather than substance abuse treatment.

This, combined with the criminal activities that many IDUs pursue to maintain their addictions, means that they are frequently arrested and imprisoned. This tends to reinforce the public's perception of them as "bad" people and of drug use as a crime rather than a medical and behavioral problem.

◆ **Funding priorities.** The federal government currently spends nearly twice as much on programs to stop drugs from entering the U.S. as on programs to reduce the demand for drugs. In 1998, two-thirds of the \$16.18 billion federal drug control budget was allocated for "supply reduction" activities, such as border control efforts, and one-third for "demand reduction" activities, such as prevention and treatment programs (ONDCP, 1999 in Amaro, 1999). The drug control budget for fiscal year 2000 is expected to increase by over \$1.6 billion, but the proportion dedicated to demand reduction will be only slightly augmented (Amaro, 1999).

◆ **Limited substance abuse treatment services.** It is clear that the people who need substance abuse treatment far outnumber the people who are able to receive it. For example, data from the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Household Survey on Drug Abuse (NHSDA) show that in 1996, more than 5.3 million people with severe substance abuse problems needed treatment services. However, only 37 percent received such treatment (Epstein and Gfroerer, 1998). Of the estimated 600,000 opiate-dependent individuals in the U.S., only about 115,000 (19.2 percent) are in methadone maintenance treatment (NIH, 1997). Part of this results from a lack of funding. Other contributing issues include a shortage of physicians and other health care professionals who are trained and able to provide treatment; complex federal regulations that limit the flexibility and responsiveness of treatment programs; limitations in health insurance coverage for treatment; and an existing patchwork of federal, state, and

local regulations and funding mechanisms that limit providers' ability to provide the continuum of services necessary to meet the complex substance abuse treatment, medical, and social service needs of injection drug users (AED, 1999; NIH, 1997).

Community resistance to substance abuse treatment facilities and programs—the "not-in-my-backyard" (NIMBY) factor—also plays an important role in limiting the availability of treatment and other services for IDUs. Common objections to these facilities are that they contribute to an increase in crime in the area, attract undesirable groups of people, and import the drug culture. As a result, treatment facilities are often located in industrial or run-down parts of town to avoid the presence of residential neighbors and diminish the possibility of community resistance. Treatment program counselors also may routinely patrol the area around their facility to ensure that clients do not loiter and cause problems with neighbors.

During 1999, a number of prominent voices spoke out on these issues and in favor of major increases in the funding and attention devoted to substance abuse treatment:

• General Barry McCaffrey, Director of the Office of National Drug Control Policy (ONDCP), proposed a new strategy of integrating drug testing and substance abuse treatment into almost every phase of the criminal justice process, from arrest to the return to community after prison. Gen. McCaffrey outlined this strategy at a "National Assembly on Drugs, Alcohol Abuse and the Criminal Offender," which was sponsored by the ONDCP, the Department of Justice, and the Department of Health and Human Services to bring together 900 law enforcement, prison, and public health specialists from around the country to discuss ways to break the seemingly unbreakable link between substance abuse and crime. The assembly advocated better collaboration between substance abuse, public health, and

criminal justice, much greater reliance on substance abuse treatment to address the cause of most involvement with criminal justice, and better programs to ease inmates' return to their home communities after prison (Wren, 1999).

- Dr. Alan Leshner, Director of the National Institute on Drug Abuse (NIDA), made the case that as a society we should no longer focus on unanswerable questions about the morality of treating versus punishing those addicted to drugs, but instead should focus on the practical benefits to individuals and society as a whole of treating drug addiction. "If we are ever going to significantly reduce the tremendous price that drug addiction exacts from every aspect of our society, drug treatment for all who need it must be a core element of our society's strategies" (Leshner, 1999).
- Dr. Hortensia Amaro of Boston University School of Medicine argued that limited funding for substance abuse treatment is an expensive long-term policy. She noted that the federal government's policy of spending nearly twice as much on reducing the supply of drugs as on reducing the demand for them through prevention and treatment programs is "perplexing" given that treatment has been shown to be more effective than law enforcement and incarceration in reducing the demand for illegal drugs. "Providing treatment to all in need could save more than \$150 billion over the next 15 years, at a price tag of just \$21 billion in treatment costs. Funding treatment for persons addicted to drugs is prudent fiscal policy: every dollar invested in drug treatment generates \$7 in savings of future costs" (Amaro, 1999; California Department of Alcohol and Drug Programs, 1994; Rydell and Everingham, 1994).

◆ **Restrictive syringe prescription and paraphernalia laws and regulations.** In the interest of limiting drug use, a number of laws restrict the purchase and possession of equipment used to prepare and administer

injection drugs. They fall into several major categories:

- *Drug paraphernalia laws* in many states make it illegal to distribute or possess any equipment intended for injecting, smoking, or otherwise consuming illegal substances (AED, 1997; Case et al., 1998; Gostin, 1998; Koester, 1994). Currently, 44 states have such laws.
- *Prescription laws* require that a person wishing to buy syringes have a valid medical prescription for syringes. In addition, some states require that syringe purchasers show

### Differences among providers of services to IDUs are caused by:

- *lack of knowledge about issues beyond one's expertise*
- *specific training and educational perspectives*
- *attitudes toward users*
- *personal experience with addiction and recovery*
- *experience working with IDUs*

identification and provide their name, address, and other identifying information (AED, 1997). Until recently, eight states had prescription statutes (Gostin, 1998). In 2000, New York, Rhode Island, and New Hampshire partially or completely removed their prescription laws. In the states in which these laws are in effect, physicians are allowed to prescribe

hypodermic equipment only for medical purposes (AED, 1997).

- *Pharmacy regulations or practice guidelines* in 23 jurisdictions restrain pharmacists from selling sterile syringes or impose additional requirements on customers for their purchases. In addition, some drug stores have corporate or individual policies that limit over-the-counter sales of syringes (Jones and Taussig, 1999).

Other related laws and restrictions include the Mail Order Drug Paraphernalia Act, which permits federal enforcement against individuals who knowingly sell or distribute syringes to IDUs, and a Congressional prohibition against federal funding for syringe exchange programs (SEPs) (Gostin, 1998).

◆ **A fragmented and polarized atmosphere.** Current public policies and restrictive laws and regulations are an important factor constraining efforts to develop comprehensive and effective interventions for IDUs. Another critical factor is the profound differences in training, experience, attitude, and approach among the various professionals who provide services to IDUs (for example, those working in infectious disease prevention, substance abuse treatment, mental health, criminal justice, and primary care). These philosophical and practical gulfs foster an atmosphere of polarization, work against a coordinated, collaborative approach, and hinder system-wide efforts to reach IDUs. The gulfs emerge from lack of knowledge about issues outside of one's own expertise, specific training and education perspectives, attitudes held toward users, personal experience with addiction and recovery, and experience working with IDUs.

One example of these differences is the debate over the relative merits of various substance abuse treatment approaches. Recovery from addiction is a day-by-day, minute-by-minute, sometimes precarious balancing act in which the user makes repeated, sequential decisions not to use. Relapse can be common. Traditional

substance abuse treatment models have focused exclusively on abstinence as the only acceptable short- and long-term outcome. A person or program that appears to tolerate any use of drugs is seen as enabling the user to continue his or her addiction. Treatment approaches that focus on abstinence from alcohol and drug use include detoxification programs, inpatient and outpatient programs, and peer-based residential treatment settings (called therapeutic communities). These approaches are usually complemented by self-help or “12-Step” programs, such as Alcoholics Anonymous, Narcotics Anonymous, or Cocaine Anonymous (AED, 1997). All have the ultimate goal of helping an individual achieve and maintain a drug-free recovery (to become “clean and sober”).

### Traditional substance abuse treatment approaches:

- *detoxification*
- *inpatient/outpatient programs*
- *methadone maintenance*
- *peer-based residential treatment settings*
- *self-help programs*

Another approach, methadone maintenance treatment, has been used for more than 30 years to treat tens of thousands of individuals addicted to opiates. Consistent participation in methadone maintenance programs over time diminishes and often eliminates use of other opiates, with con-

sequent benefits of reduced transmission of HIV and other blood-borne infections and reduced criminal activity (NIH, 1997). The effectiveness of this approach is dependent on a number of issues, including adequate dosage, the length and continuity of treatment, and the presence of associated psychosocial support services. Though considerable research supports the effectiveness of methadone maintenance treatment and it is a legally sanctioned treatment in most states, its use is very highly regulated by federal and state agencies, it is still controversial, and less than 20 percent of opiate-dependent individuals have access to it (NIH, 1997).

Another perspective on working with IDUs, called risk reduction or harm reduction, sees the fundamental problem as the adverse consequences of continued drug use (Des Jarlais et al., 1993). This approach is based on a recognition that many IDUs and other drug users are initially unwilling or unable to stop drug use and that many things can be done to help protect them, their families, and society from the harmful consequences of the drug use until they are able to stop using. Because HIV, hepatitis B, and hepatitis C infections are transmitted through shared injection equipment, it is possible for active users to reduce the risk of or prevent infection (Des Jarlais et al., 1993). Primary HIV-related risk reduction approaches include a range of interventions, such as substance abuse treatment to reduce or stop drug use; referrals to HIV-antibody testing and medical care services; referrals to social support services; education about ways for IDUs to increase control over when, how often, where, and with whom they inject; and efforts to encourage active users to switch to non-injection forms of drug use. For those IDUs who are unable or unwilling to stop injecting, risk reduction interventions also focus specifically on injection practices — providing access to sterile syringes through exchange programs or over-the-counter sales from pharmacies; emphasizing the need to never share syringes, water, or drug preparation equipment;

emphasizing bleach disinfection for IDUs who do not have sterile syringes; and providing alcohol swabs to clean injection sites to help prevent abscesses and other infections. A recent analysis of the laws in the 50 states, the District of Columbia, and Puerto Rico found that physicians in nearly all of these jurisdictions may legally prescribe sterile syringe equipment to prevent

### Risk reduction approaches:

- *substance abuse treatment*
- *referrals to HIV-antibody testing, medical care, and social services*
- *providing education about ways to manage drug use and gain control over daily life issues*
- *reduction in risky injection practices*
- *access to sterile syringes*
- *working with injectors who choose to attempt abstinence*
- *focusing on “treatment readiness”*

disease transmission and that pharmacists in most states have a clear or reasonable legal basis for filling the prescription. While physician prescription will likely not result in widespread access to sterile syringes, it may have an important beneficial impact among individual IDUs who cannot or will not stop injecting (Burriss et al., 2000).

All of these approaches have strong advocates as well as fierce opponents. Defenders of abstinence-only interventions argue that tolerating any drug use is unacceptable because it allows users to continue their self-destructive behavior and prevents them from achieving a “drug-free” status. Specifically, they express concerns that promoting syringe exchange programs and safer injection practices serve to encourage continued drug use, that methadone maintenance programs merely substitute one addicting drug for another, and that support for risk reduction approaches is an opening wedge for the eventual legalization of drugs. Many advocates of abstinence-based substance abuse treatment are former drug users for whom this approach was essential to recovery. Their experience is the foundation of their conviction that abstinence is the only valid strategy for helping IDUs to stop using drugs.

Defenders of methadone maintenance treatment cite its effectiveness in reducing dependence on illegal drugs and in helping users become productive members of society.

Defenders of risk reduction cite as compelling reasons for pursuing their approach the limited number of substance abuse treatment slots available, the fact that many users are unable or unwilling to permanently and completely stop their drug use, the importance of injection drug use in the HIV and hepatitis epidemics, and the importance of injection drug use in other health problems such as abscesses and endocarditis. Another strength, they say, is risk reduction’s underlying principle of beginning any efforts with users at the place where they are, which then allows providers to help them move to a new and better place where risk is reduced.

A 1998 U. S. House of Representatives debate on legislation to prohibit federal

funding for syringe exchange programs highlights the polemics involved in the debate over approaches to working with IDUs and illustrates some of the attitudinal and philosophical perspectives described earlier in this chapter (U.S. House of Representatives, 1998):

*“Mr. Goodlatte. Not only are needle exchange programs inconsistent with federal law, the results of community-based needle exchange program have been disastrous. Needle exchange programs have resulted in communities with higher crime, communities that are littered with used drug paraphernalia, and communities that are magnets for drug addicts and the high-risk behavior that accompany them. . . . I urge my colleagues to support this legislation, oppose the use of needle exchange programs, and make sure that we continue the fight on drugs in a sensible way by cracking down on drug traffickers and educating people in the country about the dangers of using illegal drugs.”*

*Ms. Woolsey. Maintaining the ban [on federal funding for needle exchange programs] will not help save our children or anyone else. In fact, the ban on needle exchange actually threatens lives. . . . In 1995, needle exchange programs were found to reduce the spread of AIDS and not to lead to increased drug use*

*This bill would ignore the science by denying public health experts a tool in the fight against AIDS, a tool that has been proven to slow the spread of this deadly disease. And those of my colleagues who are worried that free needles increase drug usage have to stop and think. We have to be reassured that knowing that the positive step by a drug user to choose clean needles is actually a first step in a very positive way towards their recovery. Just think about it. This is an opportunity to begin the healing process.”*

## Conclusion

As seen in this chapter, the social, legal, and public policy climate surrounding drug use creates structural and environmental barriers that limit the ability of IDUs to stop their drug use and reduce their risks of acquiring or transmitting infection. For

example, IDUs are advised to enter substance abuse treatment and, if they continue to inject, to use only sterile syringes. However, insufficient substance abuse treatment capacity and syringe laws that make it illegal to obtain or possess sterile injection equipment often make it difficult or impossible to carry out this public health advice.

This climate presents a multi-layered challenge for program staff, policy makers, and others in the public health community. Many types of services and interventions currently exist to serve the complex drug-related, medical, and social circumstances of IDUs and their families. More of these services and interventions are clearly needed, but if they are to be successful, public health program staff, service providers, and policy leaders need to design them with this existing social, legal, and policy climate in mind. This is because the social attitudes and structural factors described here often substantially limit program activities and contribute to a fragmented service delivery system that does not ensure the availability of a full range of high-quality services that IDUs can easily obtain. Services and programs need to be organized and delivered in such a way that prevention messages and public health strategies can be reinforced across IDUs’ various circumstances, patterns of drug use, stages of change of risk behaviors, and across the many community and institutional settings where they are found. At the same time, individual services need to be supported by a philosophical framework that moves beyond the stigma surrounding IDUs, reduces the current polarization among different approaches to working with IDUs, and ensures that collaboration is integral to the provision of services. The next chapter provides further detail on this vision of a comprehensive approach to preventing HIV and other blood-borne pathogens among IDUs.

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# A Comprehensive Approach is a More Effective Approach

*Prevention planners, program staff, policy makers, community-based organizations, and others who work with IDUs must deal with several significant and interrelated problems:*

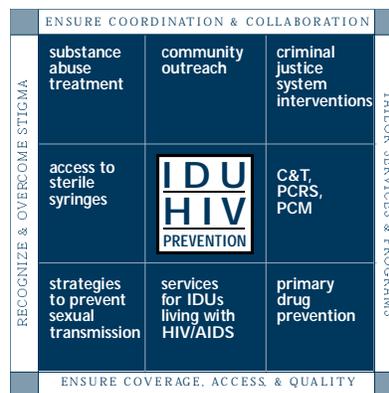
- *the high risk of infection with HIV and other blood-borne pathogens, particularly hepatitis B and C;*
- *a range of sex and drug use behaviors that maintain the epidemics and facilitate their transmission to non-infected IDUs as well as to the larger population of sex partners, children, and other adults who do not inject drugs;*
- *attitudes of bias and stigma that marginalize and dehumanize IDUs and that limit options for prevention through their negative influence on laws, regulations, social policies, and access to services; and*
- *profound and deeply held differences of philosophy and orientation among providers and organizations, which cause polarization and fragmentation, hinder cooperative working relationships, and ultimately, limit the effectiveness of services and interventions for IDUs.*

*These problems are hard to solve. Their complexity, interconnectedness, and deep-rooted nature require a comprehensive and multifaceted approach. This chapter proposes and describes such a comprehensive approach.*

Though many services and interventions can be used to help IDUs, this approach focuses on eight specific strategies and four underlying principles. **Figure 1** illustrates the comprehensive approach and shows how its components are linked. The eight strategies, clustered around the concept of HIV prevention for IDUs, are supported and framed by the cross-cutting principles of collaboration, tailoring, overcoming stigma, and ensuring coverage, access, and quality.

A range of strategies are included because a single type of service or program (substance abuse treatment, HIV prevention education, access to sterile syringes) is not enough. Multiple services and programs delivered in multiple settings are needed. The supporting principles are included because if the strategies are to succeed, the providers, health departments, and

**Figure 1**



community organizations who plan, deliver, and monitor them must consciously focus not only on “what” to pursue but also on “why” and “how” they will be pursued. Each principle contains the seeds of positive

action that will allow communities, agencies, and providers to come together and act more effectively.

The remainder of this chapter defines and describes the four supporting principles and the eight key strategies for preventing blood-borne diseases among IDUs. Accompanying these descriptions are vignettes about selected programs around the country that are working with IDUs. Although many of these programs provide similar types of services and all employ multiple components of the comprehensive approach, the vignettes are intended to highlight one or another strategy or principle and show the way in which each program’s unique approach, content, or philosophy brings that particular principle or strategy to life. Many other exemplary programs throughout the country are incorporating

## Cross-Training for HIV/AIDS, Infectious Diseases, and Substance Abuse Providers: A Novel Idea Becomes a Nationwide Trend

In 1996, the Georgia Department of Health received funding from the Center for Substance Abuse Treatment (CSAT) of the federal Substance Abuse and Mental Health Services Administration (SAMHSA) to develop and deliver a series of workshops to bring together staff from the state's public health and substance abuse treatment agencies. CDC also participated by providing technical assistance and oversight. The genesis of this project was the fact that the shift of the epidemic toward IDUs and disadvantaged and minority populations meant, increasingly, that providers were working with clients who had multiple problems. Having providers focus only on a client's substance abuse problem, or STD, or high-risk sexual behaviors was clearly not adequate. But significant barriers prevented these professionals from providing more comprehensive services. Staff from public health or substance abuse treatment didn't know what questions to ask to assess a client's problems in the other arena, or felt it wasn't appropriate to ask those questions. Federal confidentiality protections precluded substance abuse treatment and public health staff from discussing a client who was being seen at both types of facilities. Longstanding patterns of limited communication between the different agencies created an additional barrier.

Clearly, something was needed to help break down these barriers and foster collaboration. Staff needed an opportunity to learn about each other's subject areas, client assessment procedures, and treatment options. More than that, they also needed an opportunity to make personal connections across agency disciplines, cultures, and bureaucracies—connections that would allow them to develop mutual respect and a common vocabulary, foster a willingness to hear each other's point of view, and understand the realities of each agency's funding and policy requirements. The desired outcome? Collaborative working relationships, strong channels of regular communication, and ultimately, system-wide positive change.

Over a 7-month period in 1997, 24 2-day workshops were held across the state. About 1,100 nurses, counselors, social workers, clinicians, and epidemiologists participated. The first part of each workshop focused on one of the biggest difficulties—lack of knowledge. The trainers provided the public health participants with a "Substance Abuse 101"; the substance abuse treatment participants received the same for STDs. The entire group received an update on the HIV/AIDS and TB epidemics. The remainder of the workshop emphasized skills-building so that participants could conduct more comprehensive prescreening, risk assessment, and counseling with clients. Throughout the workshop, participants were encouraged to talk with each other, share experiences, and learn about the day-to-day realities and challenges faced by others.

An essential element in the success of the workshops was including all the involved parties in planning and implementation. Before the workshops, high-level administrators and front-line staff from the public health and substance abuse treatment agencies met to discuss existing barriers to collaboration, needed tools and skills, and goals and objectives for the workshops. They also discussed Qualified Service Organization Agreements (QSOA), which would allow substance abuse treatment and public health provider agencies to share limited information about clients within the legal constraints of federal confidentiality protections.

The response to the workshops was immediate, powerful, and positive. They changed attitudes, altered the way that many participants

worked with clients, created collaborations, and led to requests for further trainings. Since then, several other series of cross-training workshops in Georgia have helped participants develop new approaches to dealing with issues such as substance abuse treatment planning, harm reduction, and confidentiality.

In 1998, CSAT, CDC, and the Health Resources and Services Administration (HRSA) developed an interagency agreement to expand the cross-training concept. This initiative, called "HIV/AIDS, TB and Infectious Diseases: The Alcohol and Other Drug Abuse Connection," provides training and technical assistance to state infectious disease and substance abuse health care delivery systems so that they can more effectively serve individuals who have or are at high risk of having concurrent conditions. During FY99 alone, 13 cross-training workshops were held in 6 states. In addition, trainers have responded to 40 requests for cross-training information and technical assistance from states and federal agencies.

Many components and principles of the early cross-training experiences have been applied in the current initiative:

- **Reflect the diversity of the epidemic.** Because success in one area is dependent on addressing others, the workshop now covers prevention, treatment, and care issues for the various substance abuse and infectious disease topics (HIV, STDs, TB, hepatitis). Workshop planners and participants include representatives from mental health and criminal justice as well as from infectious diseases and substance abuse. Planners report that this greater diversity in the cross-training helps participants more easily appreciate and understand other points of view and approaches than does a workshop with more restricted representation or content.
- **Tailor to the local community.** Before a workshop is held, planners research the disease issues in the community to ensure that topics and skills building exercises reflect and are tailored to the needs, cultures, and languages of the community. Participant lists reflect the particular needs and existing service delivery systems of the community. Planners also select workshop trainers with this principle in mind.
- **Build local commitment and capacity.** Although a request for a cross-training workshop may come from one agency or organization, all the potential partners must agree to support and participate in the training. They are also part of the planning group, select the participants, and identify local co-trainers. All of these activities help to build local capacity for further training and encourage widespread institutional commitment to improving prevention, treatment, and care systems.
- **Follow up.** An essential element of the initiative is long-term follow up to track changes that result from workshops (Are trainings being replicated? How many QSOAs have been signed? Have other types of collaborative activities developed?) and to provide necessary technical assistance to states.

For more information: *HIV/AIDS, TB and Infectious Diseases Cross-Training: The Alcohol and Other Drug Abuse Connection.*  
[www.treatment.org/Topics/infectious.html](http://www.treatment.org/Topics/infectious.html)

these same approaches and philosophies in their work with IDUs. Readers also are encouraged to read Appendix A, which provides expanded discussions of the eight key strategies, including findings from research and programs and descriptions of issues and barriers facing providers and agencies as they seek to accomplish their goals.

### Guiding Principles

#### ENSURE COORDINATION AND COLLABORATION

Current medical care, social service, and HIV and drug use prevention and treatment systems are complex and governed by a patchwork of federal, state, and local funding arrangements and regulatory environments (AED, 1999). Service providers report frustrations with the barriers these multiple systems create and the ways in which they limit providers' ability to provide a continuum of services to meet the complex needs of injection drug users (AED, 1999). If interventions with IDUs are to succeed, agencies and providers must find ways to work within these systems to coordinate their efforts.

This principle also embodies another idea—collaboration. The profound and often conflicting differences in approach

and orientation espoused by various organizations, philosophies, and providers, and the resulting reluctance of agencies and providers to work together for IDUs contributes to the fragmented service delivery system and leads to policies, laws, and regulations that can be inconsistent, contradictory, and sometimes at cross-purposes. Providers, agencies, and policy makers must collaborate, sharing their various skills, perspectives, and experiences, building on prior relationships, and reaching out to groups with whom they may not have worked before. Partners in this effort need not agree on everything, but they do need to find ways to cooperate so as to achieve the larger goals of reducing HIV and viral hepatitis infection in injection drug users and reducing substance abuse.

#### ENSURE COVERAGE, ACCESS, AND QUALITY

Programs and interventions will not be effective if they do not reach a critical mass of people who need them, if IDUs cannot or will not use them, or if they are of poor quality. The first of these elements, coverage, concerns whether services or interventions are reaching a sufficient number of IDUs to make a real difference. For example, it is estimated that only a small percentage of

those needing substance abuse treatment actually receive those services (Epstein and Gfroerer, 1998). Similarly, pharmacies and syringe exchange programs help a growing number of IDUs who continue to inject to

#### A comprehensive approach rests on 4 basic principles

- *ensure coverage, access, and quality*
- *ensure coordination and collaboration*
- *overcome stigma*
- *tailor services and programs*

obtain sterile syringes. However, these programs often fall short of reaching all those who desire to reduce their transmission risks by obtaining and using sterile syringes (Lurie et al., 1998; Remis et al., 1998).

## SPHERE

### One-stop Shopping to Help Programs Work Better

The Statewide Partnership for HIV Education in Recovery Environments (SPHERE) develops and delivers training to substance abuse treatment providers, AIDS service organizations, and community-based health centers in HIV/AIDS prevention and substance abuse issues and related topics such as capacity building, policy development, organizational development, and coordination and collaboration. Increasingly, programs are calling SPHERE for help in developing long-term training and development plans and this contributes to system-wide positive change.

Funded by the Massachusetts Department of Health's AIDS bureau and its substance abuse treatment bureau, SPHERE's primary goal is to foster and support interdisciplinary collaboration across the many groups that work with substance abusing populations and those at

risk of or infected with HIV and other blood-borne pathogens. By holding cross-trainings and educational workshops and conducting outreach to HIV/AIDS, substance abuse, syringe exchange, mental health, primary care, and other providers, SPHERE hopes to create a synergy among providers so that they can learn with and from each other, share best practices, and overcome philosophical barriers.

In addition to its trainings and efforts to foster collaboration, SPHERE has developed a number of tools and forms that have been adopted by many organizations and service providers in the state. Among these are new standardized intake and record release forms and a comprehensive HIV risk assessment tool and a program satisfaction and evaluation tool.

For more information: SPHERE, Brockton, MA, 800/530-2770.

The second concern, access, relates to issues such as the number and location of prevention and care services and programs, whether they are free or not, whether IDUs need a referral to use them, and whether IDUs know about their availability. Problems with access stem from the very nature of IDUs' lives as well as from the way in which the services and programs are organized and delivered. IDUs may not know what services are available to them, how to get to them, or how to use them. Frequently, their lives are so dominated by the demands of their addiction that participation in organized interventions is beyond their capability. Further, when IDUs do attempt to use care systems or programs, they report that some procedures and staff are insensitive and demeaning, confidentiality is not protected, and agency policies effectively pose barriers to care (NYHRE, 1998; Rogers et al., 1998;

Thaca, 1997). This creates powerful feelings of mistrust and alienation and a strong reluctance to seek out or participate in programs and services.

The third issue, quality of care provided to IDUs, covers a host of issues such as the training and competency of service providers, the adequacy of medications prescribed (for example, are IDUs receiving a more effective dose of 80-100 mg of methadone per day [Strain et al., 1999] or only 30 mg per day?), and the provision of all necessary services (for example, are substance abuse treatment services accompanied by needed primary medical care or psychosocial services?). The ability of IDUs to comply with treatment regimens, maintain or improve their health, and reduce their risks of acquiring or transmitting HIV and other blood-borne pathogens is directly related to the quality of the prevention and care services they receive.

If agencies and providers hope to truly help IDUs, they must consider ways to effectively deal with these key issues of coverage, access, and quality as they plan, deliver, and monitor programs and services.

## RECOGNIZE AND OVERCOME STIGMA

If IDUs are to be successfully engaged in prevention efforts and if public policy is to move forward, the negative attitudes, stereotypes, and stigma attached to injection drug users and their addiction must be recognized and overcome. It is all too easy for IDUs to be dehumanized, to become "them," not "us." In fact, IDUs are "us" — they are family members, neighbors, friends, colleagues, patients. A willingness to put a human face on the problem, to attempt to understand the disease of drug addiction, and to consider IDUs as full human beings is a critical step to moving

## NEW YORK HARM REDUCTION EDUCATORS ( NYHRE )

### Focusing on Coverage, Access, and Quality

NYHRE is the largest harm reduction program in New York State. Now in its ninth year, its services also include outreach, HIV/AIDS prevention education, psychotherapy, treatment advocacy, referrals to health care, syringe exchange, and training for service providers. The ways in which it plans and provides its services and programs provide a useful perspective on the issues of coverage, access, and quality.

About 35,000 people are enrolled in NYHRE programs and the staff sees about 8,000 individuals each year. In the last three years, NYHRE has doubled in size and budget and the number of staff has tripled. Reaching a critical mass of those who need help is a long-term and often difficult process, particularly in a city like New York, which has an extremely large IDU population. However, NYHRE's philosophy of reaching as many users as possible "where they are," providing as many different types of services as possible, and creating linkages among a myriad of services and service providers are good ways to address existing gaps in coverage.

"We understand that there are reasons why people use drugs and good reasons why they are not connected to services. We take that as our point of departure," says Terry Ruefli, NYHRE's executive director, in describing the ways in which NYHRE helps IDUs break down barriers to obtaining services. For example, says Ruefli, NYHRE provides traditional services in a nontraditional way. "We have a psychotherapist, but he doesn't sit in his office and wait for patients to come to him. He sets up two chairs on the sidewalk,

and hangs his diploma on one of them. We do all our services on the street. Everything. Whatever need you have, you can get it met in this program in one way or another."

As part of its efforts to improve service quality and increase coordination among providers, NYHRE conducts harm reduction training programs. These workshops increase participants' awareness of the difficulties that IDUs face in obtaining high-quality services and provide training in the principles and practices of harm reduction. These trainings help providers learn to respect the ethnic and street cultures from which their clients come, which, in turn, helps them understand drug users, what makes sense to them, how they interpret the world, how they expect to be treated, and what kinds of interventions will be most effective.

Located in one of the poorest urban communities in the nation—the Hunts Point section of the Bronx—NYHRE has worked hard to collaborate with others on a variety of projects whose needs are defined by the community itself. Ruefli explains that NYHRE is "part of the process by which IDUs see that there's light at the end of the tunnel. They're not condemned to die of AIDS, to be homeless, to be mentally ill. We are one of the ways in which people can climb out of that."

*For more information: New York Harm Reduction Educators, Inc., Bronx, NY, 718/842-6050.*

## Working to Change Attitudes on a National Scale

Stigma toward IDUs and other drug users results from individual experiences with drug use or drug users, but it is also generated in large measure from broader societal attitudes toward drug use. Changing social attitudes is one way to affect change on an individual level. The National Institute on Drug Abuse (NIDA), a component of the National Institutes of Health (NIH), supports over 85 percent of the world's research on the health aspects of substance abuse and addiction and it is working on a number of fronts to disseminate the results of its research. This dissemination effort is helping to improve the nation's understanding of addiction and, as a result, change attitudes about drug addiction and people who use drugs. These various activities include:

- **Being clear on the terminology.** NIDA carefully crafts the language it uses to talk about addiction and individuals who use drugs so that it reflects current scientific knowledge and is clearly understandable. These words and phrases — “addiction is a brain disease,” for example — are used repeatedly and in multiple contexts so that, eventually, they can become a permanent part of the way that society talks about this issue.
- **Fostering dialogue with communities.** Since 1996, NIDA has hosted a series of 1-day Town Meetings in communities across the country to help bridge “the great disconnect” — the dichotomy between the public's perception of drug addiction and the scientific facts. These meetings, which are tailored to meet local interests and needs, give NIDA the chance to provide communities with the latest findings from drug abuse prevention and treatment research. They also give communities—local civic leaders, health care providers, parents, teachers, concerned citizens—a chance

to tell NIDA what kind of information they need to better deal with drug problems in their community.

- **Taking information to the people.** If research findings and scientific facts are to have an impact and be useful, they need to be used. A big focus of NIDA's information dissemination effort, therefore, is creating a wide range of publications and other materials that are appealing, user-friendly, and pragmatic. For example, NIDA's recent publication, *Principles of Drug Abuse Treatment: A Research-based Guide* synthesizes 25 years of research into a series of practical principles that communities can use to develop effective substance abuse treatment programs. NIDA has also produced numerous educational booklets, slide shows, and other materials for parents, youth, and teachers.
- **Harnessing the power of partnerships.** NIDA has developed collaborative relationships with many different organizations and agencies, from Hollywood's Entertainment Industries Council, to the American Medical Association and other professional associations, to other federal agencies such as the Department of Justice and the Office of National Drug Control Policy (ONDCP), to community coalitions such as Join Together and Community Anti-Drug Coalitions of America (CADCA). NIDA works through these partnerships to promote wide distribution of information, ensure that depictions of drug use and addiction are accurate, and create a better and more thorough understanding of drugs and their effects on the brain and body.

For more information: National Institute on Drug Abuse (NIDA), Bethesda, MD, [www.nida.nih.gov](http://www.nida.nih.gov).

## A R R I V E

### Overcoming Stigma Through Investing in Human Capital

The ARRIVE Program of Exponents, Inc. is designed to improve the quality of life of traditionally underserved minorities affected by drugs, HIV/AIDS, incarceration, and poverty. Serving clients from the entire New York City area, Exponents' programs intervene with detainees, recently released inmates, people living with HIV/AIDS, and substance users and their families. The ARRIVE curriculum covers harm reduction, relapse issues, HIV care and prevention strategies, health education, infection control, and nutrition. HIV counseling, referrals to much-needed services, and peer-led support groups reinforce classroom information and help clients amplify their strengths and resources to meet their health and social challenges.

Communications and presentation classes help clients transform personal experience into marketable skills.

ARRIVE is based on a “corporate social work model,” says deputy executive director, Maria (Sam) Josepher. “It was begun by people who were corporately aware as well as people who had been in the substance abuse field for more than 30 years. We used a lot of what we learned from the business world to teach addicts — the importance of information, communication skills, respect, cleanliness — all of this is given to the client. On the social work side, the clients receive a lot of therapeutic peer support. We acknowledge the incremental steps that people make. We notice when people are dressing better, acting better, making more out of their lives.”

Started in 1988, ARRIVE now trains over 900 substance users a year, 60 percent of whom are HIV-positive. It has maintained an 83 percent retention rate over the last decade. As Ms. Josepher explains, the program is based on the premise that investing in human capital not only works, but is cost-effective. “We see people go through a transformation within 2 months,” she says. ARRIVE costs about \$1,000 per person for more than 60 hours of education, support groups, and counseling. For \$1,000 you have a person who is literally transformed, motivated, and renewed.”

Ms. Josepher illustrates this with the following story: “One of my staff is a woman who was in and out of prison for prostitution, for drugs, for burglary. She would get off drugs but couldn't stay off. She didn't have that ability. She was a heroin IDU for 20 years and on methadone for two. She came into the ARRIVE program. She saw people like herself training, counseling, and becoming part of the solution. Then we put her on a computer. She just started soaking it up like a sponge. She became a volunteer, our first part-time employee. She never went back to drugs. The last time she was in prison was about 9 years ago. Two years ago she bought a house. When she announced this at a staff meeting, there wasn't a dry eye in the place.”

For more information: The ARRIVE Program of Exponents, Inc., New York, NY, 212/243-3434 [www.exponents.org](http://www.exponents.org).

beyond the stigma. Overcoming stigma is also, fundamentally, a pragmatic necessity, for without it, the job of helping IDUs overcome their addiction and prevent disease will not be accomplished.

## TAILOR SERVICES AND PROGRAMS

IDUs have diverse languages, cultures, sexual orientations, life circumstances, behaviors, and requirements for services. One size does not fit all. In planning and delivering interventions, providers must take into account the factors that differentiate IDUs—who they are, where they are, what they do, what motivates them, who they socialize with. Programs and providers must also account for the fact that the behaviors or occupations of certain groups of IDUs, such as the mentally ill, the homeless, commercial sex workers, and those in prisons and jails, put them at particularly high risk of acquiring and transmitting infection. Tailoring interventions to the particular characteristics and service needs of recipients

will increase their effectiveness. Involving IDUs in planning, delivering, and evaluating services and interventions is one important way to make sure that they are appropriately tailored.

## Key Strategies

### SUBSTANCE ABUSE TREATMENT

Drug addiction is a chronic illness characterized by compulsive, uncontrollable drug craving, seeking, and use, even in the face of enormous negative consequences. Though nearly all addicts believe initially that they can stop on their own, most of their attempts fail to achieve long-term abstinence (NIDA, 1999). Substance abuse treatment provides the medical, psychological, and behavioral support necessary for individuals to stop using drugs and to allow their brain processes to return to pre-addiction functioning (see Chapter 2 for more detail on the changes in brain function that occur during addiction).

## Substance abuse treatment—why include it?

- *it helps users stop using drugs*
- *it helps prevent transmission because users reduce drug- and sex-related risk behaviors*
- *it has major positive effects on a user's life*
- *it's cost effective*
- *it's a good way to reach IDUs with other messages and interventions*

## WELL - BEING INSTITUTE

### Tailoring Interventions for a Specific Population of IDUs

Well-Being Institute is a drop-in day treatment center located in Detroit's inner city. It works primarily with HIV-infected, substance-abusing women who are mentally ill. These women tend to fall between the cracks of the existing health care delivery system, which is not well suited for creating and maintaining long-term relationships with such a high-risk population. The program locates eligible women through street outreach, nursing staff contacts with case managers in Detroit's HIV care network, and referrals. Through its own model of individualized nursing care, Well-Being staff help clients achieve three primary objectives: access—overcoming barriers to obtaining care for their HIV disease, substance abuse problem, or mental illness; retention—maintaining relationships with care providers over the long-term; and adherence—sticking with treatment regimens over time.

To illustrate the specific and broader pay-offs of tailoring interventions to the needs and circumstances of particular IDUs, Geoffrey Smereck, Well-Being's director, tells the story of a mentally ill woman who was also homeless, an IDU, a victim of domestic violence, and had an HIV-related cancer:

"In the course of 9 months, we got her housing, got her primary health care needs met, and made sure she kept going to her health care appointments. We got her into a substance abuse treatment program so she was getting herself off drugs. We made sure she took her HIV meds and her meds to reduce her mental illness symptoms. I ran into her 3-4 months ago and she looked great. For public policy purposes, notice how she is no longer really an infection risk to any other person. She is a thousand-fold less drain on public resources. No one will have to pick her body out of an alley somewhere. Simply getting her to take her meds and getting her to show up for regular health care appointments is a far more cost-effective way of dealing with her health problems than her showing up in an ER somewhere with her problems like an out-of-control train wreck. The kind of interventions that can prevent the train wrecks can save the public health care systems enormous amounts of money, not to mention preventing a lot of human suffering. When I talked to her, the client wanted to get into community college and into the workplace. If we can get someone to stop soaking up resources, let alone to start contributing. . . ."

*For more information: The Well-Being Institute, Detroit, MI, 734/913-4300.*

Often, because of the complexity of the disease and the frequency of relapse to drug use, treatment requires multiple episodes over a long period of time.

For injection drug users, substance abuse treatment is a powerful disease prevention strategy. Drug injectors who do not enter treatment are up to six times more likely to become infected with HIV than are injectors who enter and remain in treatment (NIDA, 1999). Because substance abuse treatment helps users reduce or eliminate the number of drug injections, it lowers the risk of infection with HIV or hepatitis that might occur through unsafe injection practices, such as multi-person use of syringes or sharing of drug injection equipment (Thiede et al., 2000). It also prevents or reduces other harmful consequences of drug use, such as abscesses and endocarditis (inflammation of the lining of the heart). Further, because drug use impairs rational decision making, which can lead to high-risk behavior, substance abuse treatment can reduce the risk of HIV and hepatitis infection that can occur through high-risk, unprotected sex.

In the last decade, the effectiveness of substance abuse treatment and its broader

social benefits have been emphatically demonstrated (Gerstein and Harwood, 1990; Hubbard et al., 1989; Metzger et al., 1998; NIDA, 1999; NIH, 1997a; Pickens et al., 1991). Successful treatment can have a major positive impact on many areas of a person's life, helping him or her improve family life, employment and health, and decrease involvement with crime. Overall, treatment for addiction is as successful as treatment of other chronic conditions, such as asthma, diabetes, and hypertension (NIDA, 1999; O'Brien and McLellan, 1996).

*Overall, treatment for addiction is as successful as treatment of other chronic conditions, such as asthma, diabetes, and hypertension.*

Substance abuse treatment makes financial sense as well. Every \$1 invested in substance abuse treatment reduces the costs of drug-related crime, criminal justice costs, and

theft by \$4 to \$7. The average cost of 1 year of methadone maintenance treatment is \$4,700 per person. The cost of 1 year of imprisonment per person is about \$18,400. When health care savings are added in, total savings can exceed costs by a ratio of 12 to 1 (NIDA, 1999).

Substance abuse treatment programs also reach drug users and their partners with other HIV prevention messages and interventions. Participation in these interventions offered in the treatment setting is associated with reduced drug- and sex-related risk behaviors (Calsyn et al., 1992; El-Bassel and Schilling, 1992; Malow et al., 1994; McCusker et al., 1993).

#### COMMUNITY OUTREACH

Many IDUs are not engaged by conventional service systems that provide treatment and prevention services or medical, mental health, or social welfare services. This is due partly to funding and capacity limitations on the part of the service systems. It is also due to IDUs' own attitudes and life circumstances. The overwhelming priorities of obtaining and using drugs often prevent IDUs from seeking out services, such as HIV prevention, that may seem abstract or

## RIVER REGION HUMAN SERVICES

### In Substance Abuse Treatment, Be Persistent and Accept Small Victories

River Region Human Services AIDS Outreach Program, located in Jacksonville, Florida, focuses on providing substance abuse treatment services to high-risk IDUs. Additional services include HIV, STD, and TB testing; group support meetings; referrals to mental health and substance abuse treatment services; sexual risk reduction education and condom distribution; and counseling and education. Over time, it has developed links and collaborative relationships with a variety of other agencies that provide substance abuse treatment, case management, and medical services. River Region recently assumed management of a 40-bed supportive housing facility.

River Region is unusual in that outreach is an integral component of its services. River Region goes out into the community to find IDUs and offer them substance abuse treatment, HIV testing, and other services. By working in the neighborhoods with IDUs, they've been able to develop trust and credibility. "We've been doing it so long, we are recognized and have a good rep," says director Marc

Gross. "Once you get one good one with all the connections, they will work with you and get their buddies into treatment."

Persistence and patience are key elements. "You have to address the substance abuse problems first," says Gross. "The other issues can come later. If the person isn't interested in treatment, don't give up. Keep after them, eventually they will come. It's not a fast process."

In addition to working in the community, River Region is the substance abuse treatment provider for the Jacksonville jail, and has recently added an HIV testing and education component to these services. Its numerous links with community-based agencies and service providers ensure continuity and consistency for inmates once they return to the community.

For more information: River Region Human Services AIDS Outreach Program, Jacksonville FL, 904/359-6088. [www.rrhs.com](http://www.rrhs.com)

unimportant in comparison. In addition, the stigma and negative attitudes experienced by many IDUs when they have worked with service providers leads them to mistrust government agencies and conventional service systems and be reluctant to obtain services. Thus, to effectively provide prevention, treatment, and care services to IDUs, it is essential to bring the services to IDUs in the settings in which they live and socialize.

Community outreach programs can make a valuable contribution to preventing blood-borne infections (Wiebel et al., 1996). These practical and relatively low-cost approaches are designed to reach high-risk IDUs and present and reinforce prevention messages in a community setting. They can be the first step in developing a relationship with drug users and ultimately linking them with services. Because they are both an individual- and community-level intervention, they help create a culture of risk reduction among drug users, their families, friends, and neighbors. This culture of risk reduction also helps to support

recovering drug users returning from substance abuse treatment and those returning to the community after time spent in prison or jail.

Community outreach is typically carried out in settings where drug users gather — on the street, in homes, in shooting galleries and crack houses, and in housing projects, emergency rooms, laundromats, and parks. Ideally, the messages and services are delivered by people with whom the drug user is familiar and likely to trust, such as peers who live in the community. Many community outreach workers are recovering IDUs themselves. A typical outreach encounter involves face-to-face communication that is intended to assist IDUs in changing their high-risk drug use and sexual behaviors. Outreach workers may give out literature on HIV and how to prevent it or provide information on available services. They also distribute condoms and bleach kits for decontaminating injection equipment and they help IDUs obtain other services in the community, such as housing assistance

### Community outreach — why include it?

- *it reaches IDUs who don't use or are missed by conventional service systems*
- *it provides services in settings that are familiar to IDUs*
- *it helps create a culture of risk reduction in the community*
- *it uses peers who are likely to be trusted by IDUs*
- *it's relatively low cost*

## TAKING IT TO THE STREETS

### A Science-based Community Outreach Program

Located in the heart of Detroit's Empowerment Zone, Taking It to the Streets' target population is low-income, underserved, at-risk and HIV-infected African American substance users. It provides health education, HIV risk reduction counseling and testing, and syringe exchange services, and collaborates closely with six of the area's largest chemical dependency treatment centers.

Taking It to the Streets was based in part on a National AIDS Demonstration Research Project supported by NIDA that looked at effective outreach to injecting drug users. The program has pioneered the indigenous leader outreach approach. It operates on the diffusion model, which focuses on the spread of ideas and practices throughout a social system from person to person. Harry Simpson, former executive director of the Community Health Awareness Group that oversees the program, describes the staff as "individuals who share the demographic characteristics as well as the life experiences" of the people they serve. "They walk the walk, and they talk the talk. Because they are often in recovery themselves, they are seen as credible role models." Simpson says also that community involvement is the "central theme in our program's design, development and implementation, and monitoring and evaluation."

Taking It to the Streets is research-based, incorporating approaches and specific strategies that have been shown to work. For example, it was one of the first programs in the state to use OraSure for HIV testing, a quick, relatively noninvasive technology with proven reliable results. Project Respect is the counseling model employed by the program because, according to Simpson, "The results of their research showed that people who had gone through a two-session contact had pretty much the same outcome as those in longer sessions. After we implemented the Project Respect Model, our return rate increased from 40 percent to more than 80 percent."

Simpson stresses that the mobility of the program is also key to its success. His staff work out of specially outfitted vans that some have called "prevention on wheels." Simpson says, "These vans let us take the service to those who need it most, rather than waiting for them to come to us."

*For more information: Taking It to the Streets, Detroit, MI, 313/872-2424*

or mental health treatment. Outreach also involves working with drug users' social and drug-using networks to diffuse prevention messages and build risk reduction skills. Outreach can also be used to recruit drug users to other activities, such as confidential risk assessments, HIV testing and counseling, and substance abuse treatment, and to distribute sharps containers for safe disposal of used syringes.

### INTERVENTIONS TO INCREASE IDUS' ACCESS TO STERILE SYRINGES

Clearly, the best solution for injecting drug users is to stop injecting and enter substance abuse treatment. However, many drug users either cannot get into substance abuse treatment programs or will not stop injecting drugs. Even those injectors who are in treatment may relapse to injecting drugs. Given these realities, several governmental bodies and institutions<sup>1</sup> have recommended consistent, one-time-only use of sterile syringes as a central strategy in the effort to reduce the transmission of HIV and other blood-borne pathogens among those

individuals who continue to inject drugs.

Most states restrict the sale, distribution, and possession of sterile syringes: 44 states have drug paraphernalia statutes, 5 states have syringe prescription statutes, and 23 states have pharmacy regulations or practice guidelines. These restrictions present significant barriers to the sale of syringes to IDUs by pharmacists, the prescription of sterile syringes to IDUs by physicians, the operation of syringe exchange programs, the safe disposal of blood-contaminated used syringes, and ultimately, to the efforts by IDUs to reduce their risks of acquiring or transmitting blood-borne pathogens (Gostin, 1998).

Three types of interrelated interventions are now being pursued in the U.S. to increase IDUs' access to sterile syringes. Several states and municipalities are working on *policy efforts* to allow increased pharmacy sales of syringes, remove criminal penalties for syringe possession, and include language in laws stating that preventing HIV and other blood-borne pathogens is a "legitimate medical purpose" for prescribing sterile syringes to IDUs who cannot or will not

stop injecting drugs. Many jurisdictions are pursuing efforts to sustain and expand *syringe exchange programs*, which provide IDUs with free sterile syringes and a way to safely dispose of blood-contaminated used syringes. Many of these syringe exchange programs also provide additional services, such as education and counseling, primary medical services, and referrals to substance abuse treatment and social services.

*Initiatives with pharmacists* provide education about the role of sterile syringes in reducing the transmission of blood-borne pathogens such as HIV and viral hepatitis, address pharmacist concerns and questions about syringe sales and disposal, and encourage changes in pharmacy policy and practice.

An individual IDU makes approximately 1,000 injections each year, which even in a moderate-size city adds up to millions of syringes and millions of injections a year (Lurie et al., 1998). Given this fact, achieving the recommendation of the one-time-only use of sterile syringes will require the coordination of all of these interventions so that every IDU who cannot or will not stop injecting will be able to

<sup>1</sup>This includes the U.S. Public Health Service, the Institute of Medicine of the National Academy of Sciences, and the U.S. Prevention Services Task Force.

## INCREASING IDUS' ACCESS TO STERILE SYRINGES

### Changing Connecticut's Syringe Laws Results in Increased Pharmacy Sales of Syringes to IDUs

In 1992, in response to a growing AIDS epidemic largely fueled by injection drug use, Connecticut modified its syringe laws to partially remove the legal barriers to pharmacy sales of syringes to IDUs. These changes included repealing the state prescription law to allow the purchase of up to 10 syringes without a prescription and modifying the paraphernalia law to allow possession of up to 10 syringes without drug residue.

An evaluation of the effect of changing Connecticut's syringe laws revealed substantial increases in pharmacy sales of syringes in high injection drug use areas compared with areas of minimal injection drug use. Furthermore, a large number of IDUs reported that they had shifted their primary source of syringes from "the street" to "the pharmacy" and reported substantially reduced rates of syringe sharing after the new laws went into effect.

Connecticut was able to successfully change the state syringe laws because of collaborative efforts between the state health department and the Department of Consumer Affairs, the state's pharmacy regulatory body. Since 1992, there have been several collaborative efforts between the health department and pharmacy schools and organizations to educate pharmacists about the changes in the law and the important role pharmacists can play in helping active IDUs obtain sterile syringes, and to encourage pharmacists to sell syringes to IDUs to help prevent transmission of HIV and other blood-borne pathogens. Other states, including Maine, Minnesota, and Washington, and very recently New York, Rhode Island, and New Hampshire, have used Connecticut's experience as a model in their efforts to change laws and regulations restricting syringe sales.

*For more information: Groseclose et al., 1995; Valleroy et al., 1995.*

obtain and safely dispose of a sufficient number of sterile syringes to prevent the acquisition or transmission of blood-borne pathogens.

In October 1999, the American Medical Association (AMA), the American Pharmaceutical Association (APhA), the Association of State and Territorial Health Officials (ASTHO), the National Association of Boards of Pharmacy (NABP), and the National Alliance of State and Territorial AIDS Directors (NASTAD) issued a joint statement urging state leaders in medicine, pharmacy, and public health to coordinate action to improve IDUs' access to sterile syringes through pharmacy sales. They encouraged public health leaders to

work to reduce legal and regulatory barriers that restrict access, expand availability of substance abuse treatment, and improve options for safe disposal of syringes (NASTAD, 1999). This statement builds on previous similar policies adopted by the APhA in 1999, the AMA and NASTAD in 1997, and ASTHO in 1995.

#### INTERVENTIONS IN THE CRIMINAL JUSTICE SYSTEM

Because injection drugs are illegal and drug users often resort to crime to support their drug addiction, IDUs are frequently arrested and imprisoned. A recent study on substance abuse and prisoners found

that 81 percent of state inmates, 80 percent of federal inmates, and 77 percent of local jail inmates had some type of drug abuse problem (Belenko, 1998). In 1996, an estimated 250,000 state prison inmates had injected drugs, including 120,000 who had shared needles. Some 14,000 federal prison inmates had injected drugs, including 6,000 who shared needles (Belenko, 1998).

At the same time, inmates in prisons and jails have disproportionately high rates of HIV infection and other STDs, hepatitis, and other health problems. At the end of 1996, 2.3 percent of male and 3.5 percent of female state and federal prison inmates were known to be infected with the HIV virus (Hammett et al., 1999). AIDS was

### BROOKLYN TREATMENT COURT

#### An Innovative Approach to Working with IDUs Within the Court System

Since the early 1990s, 400 jurisdictions have established drug courts with the idea that a different approach was needed. In the drug court model, the emphasis shifts from incarceration with occasional treatment, to treatment with (hopefully) only occasional incarceration. In most drug courts, substance abusing defendants who have been charged with nonviolent offenses are screened for eligibility. If eligible, the defendant will be offered a deferred prosecution or the opportunity to plead guilty to the charges with the promise that if he or she complies with court-mandated substance abuse treatment, the court will vacate the plea and dismiss the charges. If the defendant refuses treatment or fails to fully comply, the case will be prosecuted in the usual fashion. Defendants who choose treatment regularly report back to the court on their progress. A central component of the model is monitoring of drug use through frequent drug tests. The court uses escalating sanctions for drug use and rewards for progress to create incentives for the defendant's recovery.

The Brooklyn Treatment Court (BTC) has taken this model a few steps further. What it has tried to do is recognize the myriad needs and situations of substance abusing individuals who come into the criminal justice system. These men and women are not just addicted to drugs. They have serious health problems as well as employment, housing, and social service needs. Women drug users have particularly complex situations; many have experienced physical or sexual abuse and many have child custody issues.

To accommodate these needs, the BTC has developed a broad network of on-site and off-site collaborative services. For example, the New York City Department of Health provides screening, testing, and education for HIV, TB, STDs, and pregnancy. The NYU Division

of Nursing, in collaboration with the Brooklyn Hospital, provides primary health care services. The Human Resources Administration provides assistance with welfare, food stamps, and Medicaid. The BTC also provides acupuncture and short-term drug education and intervention through its Treatment Readiness Program. The BTC's Project Connection has relationships with many local organizations, which helps clients return to their communities after treatment and promotes enhanced court-community relations. BTC also works with attorneys to advocate for women involved in child custody cases and collaborates with the Family Court and the Administration for Children's Services to coordinate case management of women who are involved in the criminal justice and Family Court systems.

In describing BTC's approach and philosophy, Valerie Raine, BTC's project director, says, "What we have tried to do here is bring as many services on site to the courthouse, so this population is not tossed around and referred out. You lose them the minute you refer them even across the street. A lot of what we're trying to do is to integrate services. Because, especially in New York, services are so frequently fragmented in a way that doesn't effectively meet the needs of the population. If you only meet one need and not the others, they are probably going to fail — to recidivate, to start using again."

The Brooklyn Treatment Court has been in operation since 1996. It has placed more than 1,525 people in treatment; more than 500 are still in treatment and about 374 have "graduated." It enjoys a high retention rate — about 60 percent.

*For more information: Brooklyn Treatment Court, Brooklyn, NY, 718/243-2639. [www.drugcourtech.org](http://www.drugcourtech.org)*

diagnosed in 0.5 percent of all inmates, a rate six times higher than that of the U.S. population. The high-risk behaviors responsible for the transmission of HIV and other blood-borne illnesses among inmates include high-risk sexual activity, sharing of needles and other drug injection equipment, and tattooing with improvised tools and materials (Calzavara et al., 1997; Dolan et al., 1996; Mahon, 1996; Struckman-Johnson et al., 1996).

In light of the many IDUs who are in the criminal justice system and the large numbers of at-risk and infected individuals, this setting is a crucial venue for HIV- and hepatitis-related interventions and services. Providing a range of health and prevention

education interventions to inmates not only benefits them and their overall health but can also improve the health of the communities to which the vast majority of inmates return (Hammett et al., 1999).

One of the most important types of interventions in prisons and jails is education and prevention efforts led by inmates themselves. These programs can be cost-effective and they have a credibility that programs led by outsiders cannot match. Peer-led programs also provide significant benefits to the peer educators themselves. Through participating in the programs, peer leaders can develop a positive focus in their lives, regain a sense of purpose and empowerment, and realize that they are able to influence

others in ways they never believed possible (Hammett et al., 1999).

Prevention services currently offered to inmates vary widely across state, county, and city jails and prisons. They include instructor-led and/or peer-led HIV education, pre- and post-test counseling, multi-session prevention counseling, the use of audiovisual materials, and the distribution of written materials. Most correctional systems provide HIV antibody testing, although testing policies differ widely. Few systems routinely screen inmates for STDs and only limited viral hepatitis prevention and treatment services are available. A very few systems make condoms available to inmates.

## THE WOMEN AND INFANTS DEMONSTRATION PROJECTS

### Preventing the Sexual Transmission of HIV at the Community Level

Currently, the number of AIDS cases are increasing faster among women than among men; heterosexual transmission is responsible for a growing percentage of these cases (38 percent of cases among women in 1997, as compared with 14 percent in 1987). Using a condom is the principal way to prevent heterosexual transmission, but its use is relatively low among the male partners of women at risk and is partner-specific, meaning that rates of use are lower with main partners than with other partners.

The Prevention of HIV in Women and Infants Demonstration Projects (WIDP) was a 5-year, multi-site intervention designed to increase positive attitudes, behaviors, and community norms around condom use among women at risk of HIV infection. Using the stages of change theory, social learning theory, and the diffusion-of-innovation theory, the WIDP built on strategies previously applied in CDC's AIDS Community Demonstration Projects to see whether a variety of HIV prevention activities focusing on the need to use condoms with main and other partners would increase the use of condoms. This 1991-1996 intervention took place in two public housing communities in Pittsburgh, a low-income neighborhood in West Philadelphia, and a group of inner-city neighborhoods in Portland, Oregon. Several other communities served as a comparison group.

The centerpiece of the intervention consisted of a series of culturally specific role-model stories that were developed for use in each community. In each story, the main character moved from one stage in the stages-of-change theoretical model to the next. In each community, 33 to 48 stories, each of which were based on interviews with women in the community, were developed and widely distributed as fliers, brochures, posters, and newsletters.

Several other activities supported these stories—a peer network of volunteers was formed to provide HIV prevention information and distribute the stories and condoms; small businesses and neighborhood organizations and agencies were recruited as distribution sites for the stories and other HIV prevention information and as sites for workshops or other activities; each intervention city also hired four full-time outreach workers to provide individualized HIV prevention information and condoms to women in the community.

The WIDP reached large numbers of at-risk women with HIV prevention messages and it was well received by community leaders, businesses, and residents. It was also effective in encouraging women to talk with their main partners about using condoms and to begin using them. There was a similar, though not statistically significant, positive change in condom use with other partners as well. One final and notable finding was that intervention effects began to appear only after the WIDP had been active for 2 years. In combination with the other findings, this suggests that to be effective in low-income, higher-risk neighborhoods, interventions need to address the particular social, economic, and cultural issues that affect the target population and they need to be sustained over the long term.

*For more information: Lauby et al., 2000.*

New antiviral and combination therapies are widely available in correctional facilities (Hammett et al., 1999). However, a number of factors, including the high cost of the regimens, inmate reluctance to seek testing and treatment, uneven clinical quality of services, and a lack of uniform treatment standards means that the availability of comprehensive care for infected inmates that involves case management, psychosocial treatment in conjunction with medical services, hospice care, substance abuse treatment, and continuity of services between prison and the community, may be limited (Hammett et al., 1999).

### STRATEGIES TO PREVENT SEXUAL TRANSMISSION

Sexual transmission of HIV and hepatitis involving IDUs is an important factor in the continuing epidemics of these diseases in the U.S. In 1997, 11 percent of the new AIDS cases reported that year were among men and women whose sex partners were IDUs. Twelve percent were among male IDUs who also reported having sex with other men (CDC, 1998a). High-risk sexual behavior is also strongly associated with hepatitis B transmission (CDC, 1999). As described in Chapter 1, high-risk drug behaviors and high-risk sexual behaviors are often linked (Chu et al., 1998). For example, a large portion of IDUs use alcohol and/or crack cocaine, which are often associated with increased frequencies of unsafe sexual behavior (Edlin et al., 1994) and number of sex partners (Corby et al., 1988). Some IDUs support their drug habits by exchanging sex for money or drugs. Therefore, the extent to which IDUs change their sexual behaviors in response to these diseases is critical. This is particularly true in light of the fact that although IDUs will make large changes in their injection risk behavior in response to concerns about AIDS, changes in sexual behavior are generally more modest (Des Jarlais, 1995; Friedman et al., 1993). In addition, it appears that IDUs are more likely to reduce sexual risk behaviors with

casual sexual relationships than with their primary sexual partners (CDC/ACDP, 1999; Friedman et al., 1994; Friedman et al., 1999) or with sexual partners who do not inject illicit drugs (Friedman et al., 1994; Friedman et al., 1999; Vanichseni et al., 1993). The reluctance to use condoms with main partners may be due to concerns that doing so violates the intimacy and trust developed in the relationship.

To date, distributing condoms and information has commonly been used to help IDUs reduce their risk of sexual transmission. These materials are given out for free by most outreach workers, syringe exchange and other risk reduction programs, drug users' organizations, and some substance abuse treatment programs. One-on-one sexual risk reduction counseling and group interventions are also conducted by peers to address skills building and rehearsal, interpersonal communication, problem-solving, situational analysis, and self-management strategies. Strategies for female drug users and sexual partners of drug users have stressed the importance of building self-esteem, social supports, and sexual negotiation skills to encourage safer sex practices with partners.

In developing strategies to reduce sexual transmission among IDUs, agencies and organizations should design them with specific target groups (for example, in-treatment versus out-of-treatment drug users) and specific goals (for example, preventing acquisition of infection in uninfected IDUs and preventing transmission from infected IDUs to others) in mind. These strategies should also take into consideration the determinants of sexual transmission, including the consistency of condom use, the presence of concurrent STDs, the presence of concurrent injection drug and crack use, and the extent of sexual activity while high. Interventions designed for the sexual partners of IDUs are an important complementary element of overall strategies for reducing sexual transmission among IDUs.

### HIV COUNSELING AND TESTING, PARTNER COUNSELING AND REFERRAL SERVICES, AND PREVENTION CASE MANAGEMENT

A comprehensive approach to preventing HIV and other blood-borne infections must include the opportunity for individuals to discover whether they are infected, and if they are, to help them inform their partners. If they are not infected but engage in high-risk practices, the approach can also help IDUs begin or sustain behavior changes that will reduce their risk of acquiring or transmitting the infection. Three interrelated services are designed to meet these objectives:

- HIV prevention counseling and testing;
- partner counseling and referral services; and
- prevention case management.

Because these services are one-on-one and focused around the needs of the client, they have the potential to address the complex lives and circumstances of IDUs and more effectively influence their risk behaviors than can more limited and diffuse interventions. In addition, partner counseling and referral services and prevention case management have the potential to provide the continuity of care that is so important to successful outcomes with IDUs.

*HIV counseling and testing (C&T)* is a prevention intervention that provides HIV antibody testing and individual client-centered counseling. The counseling is focused on working with the client to identify his or her risk behaviors and then to develop an individualized risk reduction plan. It provides a private and confidential way for individuals to learn their HIV serostatus and get further help, whatever the results of the testing. A number of C&T approaches have been developed that are well suited to IDUs, including new, rapid HIV antibody tests that allow a person to be tested and receive their results in one visit (CDC, 1998b), other new tests that allow testing

## Helping HIV+ IDUs Tell Their Partners

Despite the benefits of HIV testing, many people find it difficult to complete the process because of worries related to being possibly infected. Fear of partner retaliation; stigma; and future health, employment, and insurance problems all may prevent a person from discovering his or her HIV infection status and disclosing it to others.

IDUs face all these concerns and more. For example, the formality and perceived hostility of the health care system discourage IDUs from seeking testing. If they do get tested and find they are infected, finding and notifying partners may be difficult. Users may not know the names of their partners, know only street names, or lack adequate locating information. IDUs may be involved in illegal activities with partners and that makes them reluctant to reveal names. Given these realities, alternative models of providing counseling, testing, and partner notification services clearly are needed.

One such model is the Outreach-Assisted Model of Partner Notification, an intervention of the Partners in Community Health Project, located on Chicago's west side. This model expands traditional community outreach activities to include counseling and testing and partner notification. As part of their regular HIV/AIDS prevention and education responsibilities, trained indigenous outreach workers, who are already familiar figures in the community, talk to high-risk IDUs and their drug-using and sex partners about the benefits of voluntary HIV testing and partner notification. Confidential testing is offered at the intervention's neighborhood storefront office. An HIV counselor provides pre- and post-test counseling to IDUs who come in for testing and works with infected individuals to determine how partners will be notified. If an infected IDU prefers to notify partners, the counselor will help prepare the person for these conversations. The IDU can also request that the outreach workers notify the partners. In this case, the counselor provides the locating and identifying information to the outreach workers; the outreach

workers do not know the identity of the infected IDU. In the course of their regular duties, the outreach workers will locate partners and inform them of their possible exposure.

This model has a number of benefits. For one thing, it offers community-based testing and counseling in a non-threatening and familiar environment by counselors and outreach workers who are trusted by and can communicate with those who live in the neighborhood. The outreach workers' thorough knowledge of the neighborhood and its social networks makes it possible for more partners to be located and informed than if outsiders were to do it. In addition, because the outreach workers are in the neighborhood all the time and often talking with individuals, their presence does not automatically indicate that they are there for partner notification. Thus, it provides a measure of privacy and protection for partners who are notified.

This model was tested on Chicago's west side over the course of a year. During this time, the project recruited 386 IDUs. Almost all—376—returned to get their results and of these, 60 IDUs tested positive. All but one were willing to identify their partners to the HIV counselor. Rather than seeing notification by others as intrusive or unwanted, the majority—82 percent—welcomed the help and asked that the outreach staff notify one or more partners. One concern that is often expressed about HIV testing and partner notification is that notification can lead to violence, but fortunately this did not occur. Moreover, recruitment for testing continues successfully in neighborhoods where notification has occurred. These results suggest that expanding traditional community outreach to include counseling, testing, and partner notification is a viable HIV prevention strategy among IDUs.

*For more information: Levy and Fox, 1998.*

## THE C.A.R.E. PROGRAM

### Using C&T, PCRS, and Case Management as an Entry Point to Reach IDUs with Multiple Services

In 1988, Austin's Community AIDS Resources and Education (C.A.R.E.) Program first began offering services to IDUs and their drug-using and sex partners. The program offers four major types of services—counseling, testing, and partner notification; early intervention services; street and community outreach; and case management. In addition, C.A.R.E. offers TB screening, client advocacy, acu-detox (a 15-point acupuncture procedure for stress reduction and relapse prevention), and a Journey program (outpatient substance abuse treatment designed specifically for individuals living with HIV).

C.A.R.E. provides free, no-appointment-needed confidential and anonymous counseling and testing at its clinic, at two Travis County correctional facilities, and at each of the publicly funded drug treatment programs. These services are the "entry point" for 85 percent of C.A.R.E.'s clients and they lead directly into the program's other highly integrated services. C.A.R.E.'s work with jail inmates shows how this operates. Individuals who test positive for HIV while in jail are linked immediately with a C.A.R.E. community outreach worker.

This worker stays in touch with the inmate, works with the correctional facility medical staff to ensure that the inmate receives medical care, and develops a case management plan for that person that includes provisions for continuity of care and HIV medications once the inmate is released. This worker also makes sure that the street outreach team is aware of any inmates who may be released from jail earlier than expected, which helps to ensure that the person stays linked to the help he or she needs. C.A.R.E. also provides education and early intervention services to all inmates at correctional facilities. In 1999, the program educated 3,443 men and women in jails about HIV and STD prevention, safer sex practices, hepatitis C prevention, and harm reduction.

C.A.R.E. receives its funding from a variety of sources, including the Texas Department of Health, the Texas Commission on Alcohol and Drug Abuse, Ryan White Title III, and the City of Austin.

*For more information: C.A.R.E., Austin, TX, 512/473-2273 x 108.*

to be conducted with oral fluids rather than blood, and C&T settings designed to attract IDUs (CDC, 1989).

*Partner counseling and referral services (PCRS)*, formerly known as “partner notification,” begin when a person seeks HIV counseling and testing. If the test is positive for HIV, he or she is given the opportunity to receive PCRS at the earliest appropriate time. During the initial PCRS interview, the counselor will discuss with the client his or her responsibilities to sex and drug-use partners and available options for notifying them of the client’s infection. The HIV-infected client is encouraged to voluntarily and confidentially disclose identifying, locating, and exposure information for each partner. The PCRS provider and client together formulate a plan and set priorities for notifying partners.

PCRS can have important benefits for individuals and communities in that they

provide an opportunity for agencies to notify the partners of infected individuals of their exposure to HIV and, potentially to viral hepatitis also. If already infected, the partners’ prognosis can be improved through earlier diagnosis and treatment. If not infected, the partners can be assisted in changing their risk behavior, thus reducing the likelihood of acquiring the virus. From an epidemiological standpoint, following the chains of transmission from one infected individual to another within and across social networks permits public health investigators to chart the course of the epidemic and reach individuals at very high risk.

*Prevention case management (PCM)* is an intensive, ongoing, client-centered HIV prevention activity designed to help individuals with complex lives and circumstances adopt and maintain HIV risk-reduction behaviors. It provides counseling, support, and help with services to address the relationship between HIV risk and other issues such

as substance abuse, STDs, mental health problems, and social and cultural factors. Because it has the potential to address a wide range of social problems and risk behaviors, PCM is particularly suited for individuals like IDUs, who have or are likely to have difficulty initiating or sustaining practices that reduce or prevent HIV transmission and acquisition. PCM strives to develop an ongoing relationship with each client to provide an environment of trust and understanding within which prevention counseling can take place.

#### COORDINATED SERVICES FOR IDUS LIVING WITH HIV/AIDS

Because HIV disease is a chronic and complex condition with frequently changing recommendations for treatment regimens, infected IDUs and their families require close monitoring and a constantly changing array of services in their homes, in the

## HEALTH BRIDGE

### Coordinated Services Improve the Health and Quality of Life of IDUs Living with HIV

Working in upper Manhattan and the South Bronx, Health Bridge’s goal is to engage, link, and provide continuous care to HIV-infected men and women who have fallen through the cracks and are lost to follow-up within the traditional medical care delivery system. According to Debbie Indyk, director of Health Bridge, the key is to “identify strategic sites for reaching people who are not reached elsewhere, and engage them for whatever they need to be engaged for. We have lots of people with HIV who know their status but aren’t in care and lots of people who don’t even know their status. But we can reach these people if we think strategically about where to find them and establish linkages and infrastructure. Through outreach you find crises, but subsequently, you can also deal with stabilization and growth and development.”

Working closely with the Mount Sinai Jack Martin Fund Clinic and other New York City programs for IDUs, Health Bridge staff provide holistic care to HIV-infected individuals who live in single room occupancy (SRO) hotels. Through their “home visiting” approach and consistent presence in the hotels, Health Bridge staff are able to successfully engage clients and provide various services, including wound care, urgent care, entry into substance abuse treatment, and stage-based links to primary care. For those clients who are not ready to come into the clinic for care, a Health Bridge team consisting of a physician assistant, a part-time attending physician, a medical assistant,

and two case managers provide care, support, and referrals to housing, case management, and other services at the SRO hotels.

A fundamental element of the Health Bridge model is recognizing that disenfranchised individuals, such as HIV-infected IDUs, need support through various phases of engagement and retention in care. For example, clients may be willing to meet with Health Bridge staff but not come to the clinic for care; they may be ready to take AZT to reduce the risk of perinatal transmission, but not want to begin treatment for their own HIV disease. Through a model derived from the stages of change theory and using sustained outreach to reach individuals “where they are,” Health Bridge staff have built a safety net that can quickly identify people in crisis as well as those ready to be engaged in medical care, substance abuse treatment, and other care and support services.

Since its inception in 1998, Health Bridge has reached well over 100 people living in three SRO hotels. Over one-half are African American and about two-thirds are men. Recognizing the very great need in this part of New York, Health Bridge is actively trying to expand its capacity and linkages so that it can serve increased numbers of infected and at-risk individuals.

*For more information: Health Bridge, New York, NY 212/241-7863.*

hospital or health care facility, and in the community (Keenan, 1990). With appropriate and high-quality services and medications, IDUs living with HIV can lead fulfilling, productive lives.

Many IDUs continue to engage in high-risk behaviors after they learn they are infected with HIV and, thus, place others at risk of HIV infection and themselves at risk for collateral health problems (CDC, 1996; HRSA, 1994; Kwiatkowski et al., 1998; Metsch et al., 1998). When HIV-infected IDUs are actively engaged in health care, however, they can be followed to identify renewed high-risk sex or drug use and counseled about the effects of these behaviors

on themselves and others. HIV-infected drug users who are in substance abuse treatment and are receiving other health services are more likely to comply with HIV/AIDS drug treatment regimens and to reduce their sex and drug risk-related behaviors (Booth et al., 1999).

As a marginalized population, IDUs can be less connected to the AIDS service delivery system than are other infected individuals. Like non-IDU consumers, many IDUs do not know where to go to obtain services or what services are appropriate for different people at different stages of the disease. The service delivery system can be too

complex and fragmented for them to navigate and often too remote geographically, socially, and culturally. Some programs prohibit services to active drug users, which presents formidable barriers for IDUs. Negative attitudes by staff toward IDUs' behaviors and life circumstances further exacerbate the situation. IDUs living with HIV/AIDS therefore need a full complement of services, delivered in a setting geared to attract IDUs from the community and retain them. Case managers and prevention case managers should offer risk reduction counseling and prevention services to these individuals and assist them with managing their chronic and acute health care needs, including taking

## PRIMARY DRUG PREVENTION

### Community Coalitions Are Powerful Agents for Change

Over the last 25 years, many community groups and coalitions have sprung up to respond to a variety of social problems in the U.S. Among the most powerful are coalitions that have worked to prevent alcohol and drug use among youth and to achieve drug-free communities. These coalitions recognize that primary prevention is not so much a specific program – though those are important – but a process over time in which a variety of individuals and groups come together to study and then address the problem of drug abuse and related issues (Rusche, 1995). The results include strengthened organizations, more consistent policies, shared understanding of different viewpoints, changed social attitudes, and reduced drug use. Three good examples of community coalitions are:

- **Join Together** founded in 1991, which supports community-based efforts to reduce, prevent, and treat substance abuse across the nation. In 1996, Join Together broadened its scope to include gun violence prevention because of its belief that communities need to employ comprehensive strategies that respond to the harms related to substance abuse. Join Together produces reports, newsletters, and community action kits; supports a National Leadership Fellows program; sponsors public policy panels that examine and recommend changes in public policies and practices related to substance abuse; provides technical assistance designed to link people nationwide so that they can share information and resources; and conducts surveys to measure and define the community movement against substance abuse. Join Together is funded by a grant from The Robert Wood Johnson Foundation to the Boston University School of Public Health.
- **Community Anti-Drug Coalitions of America (CADCA)**, which creates and strengthens the capacity of new and existing coalitions to build safe, healthy, and drug-free communities. CADCA supports its 4,300 members with technical assistance

and training, public policy initiatives, media strategies and marketing programs, and conferences and special events. The President's Drug Advisory Council founded CADCA in 1992 and it is currently funded by The Robert Wood Johnson Foundation, the Knight Foundation, the Samuel Newhouse Foundation, the Annie E. Casey Foundation, and the K-Mart Corporation.

- **The Miami Coalition**, which is a broadly-based community organization dedicated to reducing the problems of drug abuse, addiction, and directly related social issues. The Coalition serves as a convener and facilitator, bringing together diverse local institutions and organizations to determine how Miami-Dade County can collectively tackle this major criminal justice and health crisis. These groups have included law enforcement, medicine, education, business and commerce, the corporate workplace, the faith community, media, the banking industry, neighborhoods, youth, and families. The Coalition, which was founded by Dade County's corporate and civic leadership in 1988, spent much of its founding year in a strategic planning process that resulted in a detailed analysis of community needs and resources related to the local drug problem and the formation of task forces assigned to address specific goals. This same process of analysis and response has been continued and refined each year since then.

*For more information: Join Together, Boston, MA, 617/437-1500, [www.jointogether.org](http://www.jointogether.org); Community Anti-Drug Coalitions of America, Alexandria, VA, 703/706-0560, [www.cadca.org](http://www.cadca.org); The Miami Coalition, Coral Gables, FL, 305/284-6848, [www.miamicoalition.org](http://www.miamicoalition.org). More information on primary drug prevention can also be obtained from National Families in Action, a national drug education, prevention, and policy center founded in 1977. NFIA, Atlanta, GA, 404/248-9676, [www.emory.edu/NFIA](http://www.emory.edu/NFIA).*

anti-HIV medication and opportunistic infection prophylaxis as recommended. In addition, a full range of complementary, affordable, and accessible services should be made available, including substance abuse treatment services, mental health services, and help with other basic needs such as food, housing, child care, and job training.

## PRIMARY DRUG PREVENTION

Primary drug prevention is a key strategy in a comprehensive approach to preventing blood-borne diseases among IDUs and reducing the spread to others. By helping individuals avoid drug use and drug injection altogether, these programs help eliminate the risk of injection-related blood-borne virus transmission. Primary drug prevention programs, which are conducted in a variety of settings, including schools, families, and community-based organizations and through a variety of channels, such as the media, are largely aimed at youth to encourage them to avoid or delay the age of first use of alcohol, tobacco, marijuana, inhalants, and other drugs. Avoiding or delaying substance use can help youth prevent many problems associated with it, including truancy, aca-

demie failure, violence, thefts, motor vehicle crashes, homicides, injuries, suicides, and risky sexual behaviors (Ary et al., 1999; Berger and Levin, 1993; Cohen et al., 1997; Donovan et al., 1988; Farrell et al., 1992; Osgood et al., 1988).

### Next Steps for Communities

This chapter has described the elements of a comprehensive approach to preventing the continued transmission of blood-borne pathogens among IDUs—eight strategies supported by four essential principles. Health departments, community planning groups, community-based organizations, health care and social service providers, correctional facilities, policy makers, and others who work with IDUs are already carrying out many of these elements and working in creative ways to enhance the impact and reach of their efforts.

At the same time, communities and community planning groups must deal with various realities that hamper their ability to bring individual efforts together into a truly comprehensive approach. These realities can include limited funding; restrictive laws and regulations; community opposition; a lack of trained staff; insufficient knowledge about

the extent and nature of the community's HIV, hepatitis, and injection drug use problems; a limited understanding of the community's IDU populations; or polarized political and philosophical viewpoints among different organizations and providers. What can communities do to adjust their programs to overcome these realities?

One important step that communities can take is to assess existing IDU-related prevention needs, services, interventions, and barriers in light of the comprehensive approach. The process of gathering this information does not have to involve a formal or lengthy needs assessment. Health department staff, service providers, and other interested local groups may already know much of this information or have ongoing working relationships with those who do. An important group to include in this process is IDUs themselves, for they have a unique perspective on the programs and services that are designed for them. Various reports have been written that also provide valuable background information and expert consensus on effective interventions (NIH, 1997b).

The following questions, organized around the four principles that guide the compre-

## PRIMARY DRUG PREVENTION

### Learning What Makes A Program Effective

A number of primary drug prevention programs have been rigorously evaluated and are recommended. They fall into several categories:

**Universal programs**, which are designed to reach a general population, such as all students in school —

- Project Star (Pentz, 1995; Pentz et al., 1989)
- Life Skills Training Program (Botvin et al., 1990; Botvin et al., 1995a; Botvin et al., 1995b)
- Adolescent Alcohol Prevention Trial (Donaldson et al., 1994)
- Seattle Social Development Project (Hawkins et al., 1992)
- Adolescents Training and Learning to Avoid Steroids (Goldberg et al., 1996a; Goldberg et al., 1996b)
- Project Family (Spoth, 1998)

**Selective programs**, which target groups at risk or other subsets of the general population —

- Strengthening Families Program (Kumpfer et al., 1996)
- Focus on Families (Bry et al., 1998)

**Indicated programs**, which target people who are already experimenting with drugs or who exhibit other risk-related behaviors —

- Reconnecting Youth Program (Eggert et al., 1994; Eggert et al., 1995)

**Comprehensive programs**, which include several interventions to reach the general population, groups at risk, or those already using drugs —

- Adolescent Transitions Program (Dishion et al., 1998)

*For more information: Drug Strategies, 1999; NIDA, 1997.*

hensive approach, provide a framework for communities to generate the information necessary for this assessment.

### ENSURE COORDINATION AND COLLABORATION

Successfully reaching IDUs must involve a range of services and interventions. By definition, this means that different agencies, health and social services providers, health professionals, and others active in the community must work together to plan, carry out, manage, and monitor these efforts. Understanding ongoing efforts as well as the attitudes of key players toward coordination is an essential first step to building and maintaining effective collaborations.

- What kinds of collaborations and coordination currently exist among health department staff, community planning groups, community organizations, health and social services providers, correctional institutions, policy makers, and others who work with IDUs?
- How might these collaborations be strengthened or new ones created?
- What barriers to coordination and collaboration exist (e.g., philosophical differences, organizational characteristics of service delivery systems, funding limitations, legal or regulatory barriers, lack of communication)?
- How might these barriers be overcome?
- Do the various providers who work with IDUs (such as those in substance abuse treatment, public health, primary care, criminal justice, mental health, and social services) have opportunities to learn about each others' issues and treatment approaches and philosophies (e.g., through cross-training, site visits, formal or informal networking)?
- Are IDUs involved in planning, designing, and carrying out services and interventions?

### ENSURE COVERAGE, ACCESS, AND QUALITY

Assessing services and programs from these three perspectives will provide valuable insight into the strengths of existing programs and services and the ways in which communities can build on these strengths. This exercise can also shed light on the barriers that individuals face as they attempt to obtain or participate in them and reveal gaps or weaknesses in programs that must be addressed.

#### Coverage

- Which of the eight key strategies are being carried out at present? At whom are they directed and how are they being implemented?
- How many IDUs receive which services and interventions (e.g., are there multiple outreach teams to cover the multiple neighborhoods that have injection drug use problems)?

#### Access

- Do IDUs know which prevention and care services and interventions are available to them?
- Where are services and interventions located (e.g., in a central location only, in multiple "storefront" locations across the community)?
- What must IDUs do to obtain the services or interventions (e.g., get a referral, fill out forms, be on a waiting list, pay a fee, attend weekly sessions)?
- What sort of barriers to these requirements exist and how can they be ameliorated?

#### Quality

- Do IDUs obtain services and medications in appropriate and recommended quantities (e.g., sufficient daily doses of methadone, psychosocial support services in tandem with substance abuse treatment)?

- Are IDUs able to obtain services or participate in interventions for a sufficient length of time (e.g., substance abuse treatment that extends beyond initial detoxification)?
- Do the services obtained by IDUs complement and reinforce each other (e.g., assistance with basic living needs provided along with substance abuse treatment, risk reduction counseling that covers sexual risk behaviors as well as drug use behaviors)?

### RECOGNIZE AND OVERCOME STIGMA

In addition to collecting facts about services, programs, and interventions, it will be important for those participating in the assessment to examine the community's attitudes toward IDUs, including the attitudes of the general public, providers, and policy makers. An important element of this task will be to explore the community's legal, policy, and social environment and how it affects the services and programs available to IDUs. For example, one community may have laws that penalize IDUs for carrying syringes and an outspoken citizen group that opposes syringe exchange programs. These clearly are barriers to IDUs in their attempts to obtain sterile syringes and reduce transmission risks. Another community may have laws allowing possession of a certain number of sterile syringes and a strong outreach initiative with active peer-led education groups that are successful in helping IDUs change their behaviors. Learning about attitudes and environments and how they inhibit or encourage successful implementation of programs and services is critical.

- How has the community responded to efforts to establish and expand services and programs for IDUs (e.g., substance abuse treatment programs or drop-in clinics for IDUs)?
- Is the current concept of addiction as a brain disease known and understood by providers and the public?

- How have current attitudes about IDUs and resulting laws and policies helped or hindered prevention and treatment initiatives?
- What are the current laws and regulations regarding sale, distribution, and possession of sterile syringes?
- Do syringe exchange programs operate in the community? Under what legal and organizational auspices do they operate?

#### TAILOR SERVICES AND PROGRAMS

To effectively plan and deliver prevention and care services, providers and organizations need to understand the particular characteristics and risk profiles of the various IDU populations in the community. Generating this information will help providers to more effectively reach those at highest risk.

- What are the demographic, language, and cultural characteristics of the IDUs in the community?
- Are there specific groups at particularly high risk of acquiring or transmitting blood-borne pathogens?
- If so, what are their particular patterns of drug use and sexual behavior and how do these behaviors increase transmission risk?

- What percentage of the IDUs in the community are homeless? Mentally ill? Have other serious medical conditions? In what demographic, racial, or ethnic groups do they belong?
- Do providers and service agencies have sufficient staff who are culturally and linguistically capable of working with the community's IDU populations?
- Are IDUs involved in planning, designing, and carrying out services or interventions?

Because it may not be financially possible or organizationally feasible for a community to implement all eight of the strategies described in this chapter, agencies, organizations, and providers will need to make choices and trade-offs. The information that emerges from answering the questions listed above can help communities, community planning groups, and health departments set priorities and plan programs because it will reveal gaps in services, needs for expanded or new services, and existing duplication of services and interventions. The assessment also can be useful in helping organizations match high priority needs with potential areas of collaboration as they plan activities and determine how funding, staff, and other resources are to be allocated.

#### Conclusion

*Preventing Blood-Borne Infections Among Injection Drug Users: A Comprehensive Approach* has described a critically important public health problem now facing our nation. The intersecting epidemics of injection drug use and blood-borne pathogen infection present multiple, long-term challenges that demand immediate action. If this problem is to be effectively addressed, many different groups, organizations, and individuals must work singly and together to focus on both epidemics. We hope that the comprehensive approach presented here provides some new ways of thinking about the problem and about IDUs, some starting points for dialogue and collaboration, and some avenues for constructive action. Injection drug users, their sex partners, and their children have much to gain from this new thinking, collaboration, and action. Neighborhoods, communities, and the nation also have a major stake in the success of these efforts, for reduced drug use and reduced HIV and viral hepatitis transmission have concrete and long-lasting benefits—safer streets, healthier people, and a more productive society.

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# Appendix A

## Key Strategies for Preventing Blood-borne Pathogen Infection Among Injection Drug Users

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This Appendix details the eight key strategies of the comprehensive approach. Each section describes the service or intervention and explains its importance, provides findings from research and programs, and describes the issues and barriers facing providers and agencies in that area.

### **Substance Abuse Treatment**

For injection drug users, substance abuse treatment is a powerful disease prevention strategy. Drug injectors who do not enter treatment are up to six times more likely to become infected with HIV than are injectors who enter and remain in treatment (NIDA, 1999). Substance abuse treatment helps users reduce the number of drug injections and, thus, lower the risk of infection with HIV or hepatitis that might occur through unsafe injection practices, such as multi-person use of syringes or sharing of drug injection equipment. It also prevents or reduces other harmful consequences of drug use, such as abscesses or endocarditis. Further, because drug use impedes rational decision making, which can lead to high-risk behavior, substance abuse treatment can reduce the risk of HIV and hepatitis transmission through high-risk, unprotected sex. Substance abuse treatment has broader social benefits as well because it can lead to reduced health care costs, reduced drug-related crime and associated criminal justice costs, reduced interpersonal conflicts and drug-related injuries, and improved workplace productivity (NIDA, 1999).

Drug addiction is a complex and chronic, but treatable, illness characterized by compulsive, uncontrollable drug craving, seeking, and use, even in the face of enormous negative consequences. Though nearly all addicts believe initially that they can stop on their own, most of their attempts result in failure to achieve long-term abstinence (NIDA, 1999). Substance abuse treatment provides the medical, psychological, and behavioral support necessary for an individual to stop using drugs and for their brain processes to return to pre-addiction functioning. Often,

because of the complexity of the disease and the frequency of relapse to drug use, treatment requires multiple episodes over a long period of time. Successful treatment can have a major impact on many areas of a person's life, helping him or her improve family life, employment and health, and decrease involvement with crime.

Treatment services differ in their approaches and components. They are generally divided into five major kinds of programs (AED, 1997; NIDA, 1999):

- detoxification;
- inpatient;
- therapeutic communities;
- outpatient; and
- methadone maintenance.

In addition, many drug users also participate in self-help or 12-Step programs, such as Narcotics Anonymous, Cocaine Anonymous, or Smart Recovery. By providing a crucial support network of peers who are going through similar experiences, these programs can reinforce and extend more formal types of treatment services (NIDA, 1999).

In the last decade, the overall effectiveness of substance abuse treatment has been demonstrated (Gerstein and Harwood, 1990; Hubbard et al., 1989; NIDA, 1999; NIH, 1997; Pickens et al., 1991). A number of studies have shown that persons who receive treatment reduce their alcohol and drug use and improve their legal, employment, family, social, psychiatric, and medical situations (Anglin et al., 1989; Ball et al., 1988; DeLeon, 1984; Hubbard et al., 1989; McLellan et al., 1994; Moos, 1974; Moos et al., 1990; Simpson and Savage, 1980). Overall, treatment for addiction is as successful as treatment of other chronic conditions, such as asthma, diabetes, and hypertension (NIDA, 1999; O'Brien and McLellan, 1996). Studies of methadone maintenance treatment have shown that participation in treatment is associated

with lower HIV risk behaviors as well as lower rates of HIV seroprevalence and seroincidence (Abdul-Quader et al., 1987; Avins et al., 1997; Ball et al., 1988; Blix and Gronbladh, 1991; Booth et al., 1996; Brown et al., 1988; Caplehorn and Ross, 1995; CDC, 1984; Friedman et al., 1995; Meandzija et al., 1994; Metzger et al., 1998; Metzger et al., 1993; Moss et al., 1994; Novick et al., 1990; Orr et al., 1996; Serpelloni et al., 1994; Shoptaw et al., 1997; Williams et al., 1992).

Methadone is the medication most frequently provided to IDUs in substance abuse treatment because it is the most widely available and because many IDUs inject heroin or a combination of heroin and cocaine (Battjes et al., 1991; Hahn et al., 1989; Haverkos, 1998; NIH, 1997). Methadone reduces patients' cravings for heroin and blocks its effects, thereby enabling patients to reduce heroin use and live more productive lives. The effectiveness of methadone treatment is dependent on many factors, including adequate dosing, a sufficient duration and continuity of treatment, and the presence of complementary services, such as psychosocial and medical support, counseling, and vocational training (NIH, 1997). Some patients stay on methadone indefinitely; others progress to abstinence with decreasing doses of methadone. Several other medications can be used to treat opiate addiction, including levo-alpha-acetylmethadol (LAAM) and naltrexone, but they have not been in existence as long as methadone and are not as widely used (NIDA, 1999; NIH, 1997).

Substance abuse treatment makes financial sense as well. Every \$1 invested in substance abuse treatment reduces the costs of drug-related crime, criminal justice costs, and theft by \$4 to \$7. The average cost of 1 year of methadone maintenance treatment is \$4,700 per person. The cost of 1 year of imprisonment per person is about \$18,400. When health care savings are added in, total savings can exceed costs by a ratio of 12 to 1 (NIDA, 1999).

Another compelling reason for providing substance abuse treatment is that these programs are a good way to reach drug users and their partners with other HIV prevention messages and interventions. Participation in these interventions offered in the treatment setting is associated with reduced drug- and sex-related risk behaviors (Calsyn et al., 1992; El-Bassel and Schilling, 1992; Malow et al., 1994; McCusker et al., 1992). One of the most consistent findings of both behavioral and serologic studies is that early entry and longer duration of treatment are associated with protection from HIV infection (Metzger et al., 1998). For example, twenty years of data collected in the Bronx, New York, show that longer time in treatment is associated with a lower likelihood of HIV infection (Hartel and Schoenbaum, 1998). The strongest protective associations against HIV in this population were early entry and continuous stay in methadone treatment plus higher methadone doses (80 milligrams or higher per day).

Despite clear evidence regarding the utility and effectiveness of substance abuse treatment in helping users reduce or eliminate their drug use and helping them address a host of other problems, significant barriers remain for IDUs to fully obtain these services. For example, data from the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Household Survey on Drug Abuse (NHSDA) show that in 1996, more than 5.3 million people with severe substance abuse problems needed treatment services. However, only 37 percent received such treatment (Epstein and Groer, 1998). Less than 20 percent of opiate-dependent individuals are in methadone maintenance (NIH, 1997). Many IDUs cannot afford privately-funded services, and limitations in funding restrict the number of publicly funded slots. Even for those IDUs who are in treatment, the processes and procedures associated with participation may be daunting. For example, waiting lists, delays in admissions and lengthy and cumbersome

intake processes can discourage drug users from seeking treatment. Many communities strenuously resist the introduction of drug treatment facilities in their neighborhoods, and this limits the availability of treatment for many IDUs. State and federal funding of substance abuse treatment is insufficient to make treatment available to all who need it.

The effectiveness of substance abuse treatment depends on many factors, including its goals, the length of time treatment lasts, the doses of medications that may be prescribed, links to other services, and the characteristics of the user. Limitations in all of these areas may pose significant barriers. For example, an IDU in a methadone maintenance program may receive adequate medication but not the behavioral counseling or the case management and referral to other medical, psychological, and social services that are necessary for full and effective treatment. Or, he or she may receive lower methadone doses, which compared to doses of 80-100 milligrams, are less effective (Strain et al., 1999).

### **Community Outreach**

Many IDUs do not participate in conventional service systems that provide treatment and prevention services or medical, mental health, or social welfare services. This is due partly to funding and capacity limitations on the part of the service systems and partly to barriers that limit IDUs' ability to use these systems. IDUs' own attitudes and life circumstances also determine the extent to which they use or are reached by conventional service systems. The overwhelming priorities of obtaining and using the drugs they are addicted to often prevent IDUs from seeking services, such as HIV prevention, that may seem abstract or unimportant in comparison. In addition, the stigma and negative attitudes of service providers that are experienced by many IDUs leads them to mistrust government agencies and conventional service systems and be reluctant to obtain services. Thus, to effectively provide prevention, treatment, and care services to IDUs, it is essential to bring the services

to IDUs in the settings in which they live and socialize.

Community outreach programs can make a valuable contribution to HIV prevention (Wiebel et al., 1996). These practical and relatively low-cost approaches are designed to reach IDUs at high risk of HIV and other blood-borne infections who are not in conventional service systems. They can be the first step in developing an ongoing relationship with these drug users and ultimately linking them with services. For those users who are linked to conventional service systems, outreach is an important way to reinforce educational and prevention messages and strategies. Because they are an individual- and community-level intervention, they help create a community culture of risk reduction among drug users, their families, friends, and neighbors. This culture of risk reduction also helps to support recovering drug users returning from substance abuse treatment and those returning to the community from prison or jail.

Community outreach is typically carried out in areas where drug users congregate—on the street, in shooting galleries and crack houses, and in housing projects, emergency rooms, laundromats, and parks. The messages and services are delivered by people with whom the drug user is familiar and likely to trust, such as peers who live in the community. This personal contact between outreach worker and IDU is an important reason why community outreach can be influential in helping IDUs. Many community outreach workers are recovering IDUs themselves. A typical outreach encounter involves face-to-face communication that is intended to assist IDUs in changing their high-risk drug use and sexual behaviors. Outreach workers may give out literature on drug use, substance abuse treatment, and HIV and how to prevent it, and provide information on available services. They also distribute condoms and bleach kits for decontaminating injection equipment and help IDUs obtain services in the community,

such as housing assistance or mental health treatment. Outreach also involves working with drug users' social and drug-using networks to extend and reinforce prevention messages and build risk reduction skills. Outreach can also be used to recruit drug users to other activities, such as confidential risk assessments, HIV testing and counseling, and substance abuse treatment, and to distribute sharps containers for safe disposal of used syringes.

Outreach interventions were one of the earliest HIV prevention strategies designed to reach high-risk IDUs. Results of a number of studies and programs have shown that this approach, in fact, works. It can be used to identify and contact IDUs and it creates an atmosphere in which IDUs are comfortable talking about HIV prevention. Community outreach is effective in getting IDUs to accept HIV-prevention literature, risk reduction materials, and referral services, and outreach workers have played an important role in providing condoms to high-risk populations (Anderson et al., 1996; Anderson et al., 1998). Follow-up assessments have shown that IDUs have regularly reported reductions in five major risk behaviors after participating in community outreach interventions (APA, 1996; CDC/ACDP, 1999; Coyle et al., 1998; Semaan et al., 1998; Sumartojo et al., 1997). These include:

- stopping drug injection;
- reducing frequency of injection;
- reducing multi-person reuse of syringes;
- reducing multi-person reuse of other equipment, such as cookers, cotton, and rinse water; and
- reducing crack use.

They also have reported increases in three protective behaviors (APA, 1996; CDC/ACDP, 1999; Coyle et al., 1998; Semaan et al., 1998; Sumartojo et al., 1996):

- needle disinfection;
- entry into substance abuse treatment; and
- condom use.

A number of researchers have demonstrated the effectiveness of peer-delivered interventions conducted by community health outreach workers who were formerly active drug users, and peer-driven interventions, which are conducted by out-of-treatment IDUs who are provided with guidance and structured incentives and play an active role in their social networks in HIV prevention. Overall, these studies suggest that peers, whether former or active drug users, can be effective in reaching large and diverse communities of out-of-treatment users (Broadhead et al., 1998; Carlson and Needle, 1989; Cottler et al., 1998; Friedman et al., 1993; Jose et al., 1996; Latkin et al., 1998; Neaigus, 1998; Sufian et al., 1991). They also suggest that peers are effective role models for promoting reductions in drug-related HIV risk behaviors with active drug users, but less effective in changing sexual risk behaviors (Coyle et al., 1998).

Although community outreach is clearly an important element in any overall strategy to reach IDUs, it has its challenges. By its very nature, it is client-centered and less formal and structured and therefore can be more difficult to supervise and monitor. Outreach work is demanding and workers must contend with frequently difficult conditions, including unsafe neighborhoods, inclement weather, and, for those workers who have had drug problems, situations that may challenge their own recovery. Outreach staff need reinforcement, training, and support to avoid burnout and the risk of relapse to drug use and to help them understand the lifestyles or cultures of particular IDUs (AED, 1999). Another issue in community outreach strategies that use peers is defining who a "peer" really is. Some current IDUs may not consider a former user to be their peer. Demographic differences between the

IDUs and the peer outreach workers may affect how messages are received. These differences may also make it more difficult for the workers to establish trusting relationships with IDUs.

Environmental and structural factors also may hamper the effectiveness of community outreach efforts. For example, community outreach can face active opposition in the community from powerful individuals such as neighborhood political leaders or local drug dealers. The limited capacity of many substance abuse treatment programs means that IDUs may not be able to enter treatment even if they are referred by an outreach worker. Further, existing laws and regulations, such as restrictions on the sale of sterile syringes in pharmacies or prohibitions against syringe exchange programs or criminal penalties for possession of syringes, make it hard for outreach workers to disseminate crucial prevention messages, such as the need to consistently use sterile syringes and make it hard for IDUs to follow such advice.

Finally, the relatively unstructured and unstandardized nature of community outreach work may make it difficult for providers to identify consistently effective strategies. It also may be hard to measure the outreach process and control for extraneous factors, and attrition can skew research results. Cohort effects may promote socially desirable responses among those who return for follow-up, making self-reports less valid measures of intervention effects.

### **Interventions to Increase IDUs' Access to Sterile Syringes**

Clearly, the best way for injecting drug users to avoid the problems of drug use and blood-borne infection is to stop injecting and enter substance abuse treatment. However, many drug users either cannot get into substance abuse treatment programs or will not stop injecting drugs. Even those injectors who stop drug use through substance abuse treatment may

relapse to injecting drugs. Given these realities, several governmental bodies and institutions<sup>1</sup> have recommended consistent, one-time-only use of sterile syringes to prepare and inject drugs as a central strategy in a comprehensive effort to reduce the transmission of HIV and other blood-borne pathogens among those individuals who continue to inject drugs.

Currently, IDUs obtain syringes in several ways:

- through illegal or “black market” sources, such as street drug dealers (individuals who sell drugs and syringes to IDUs), needle dealers (individuals who sell syringes to IDUs), “shooting galleries,” or friends, injection partners, or diabetics—these syringes may have been used and contaminated with blood; some dealers “reseal” used syringes in their packaging to make them appear to be new (Des Jarlais et al., 1985; Gleghorn et al., 1995; Groseclose et al., 1995);
- by purchase from pharmacies—this ensures that the syringes are sterile; and
- through syringe exchange programs (SEPs)—this ensures that the syringes are sterile.

Most states have legal and regulatory restrictions on the sale and distribution of sterile syringes: 47 states have drug paraphernalia statutes, 8 states have syringe prescription statutes, and 23 states have pharmacy regulations or practice guidelines. These restrictions present a significant barrier to the sale of sterile syringes to IDUs by pharmacists, the prescription of sterile syringes to IDUs by physicians, the operation of syringe exchange programs, the safe disposal of blood-contaminated used syringes, and ultimately, to the efforts by IDUs to reduce their injection-related risks of acquiring or transmitting blood-borne pathogens (Gostin, 1998).

In essence, IDUs are in a Catch-22 situation. They are advised to enter substance abuse treatment and, if they continue to inject, to use only sterile syringes, but major structural and environmental factors—insufficient substance abuse treatment capacity and syringe laws that make it illegal to obtain or possess sterile injection equipment—effectively reduce IDUs’ ability to carry out this advice.

Three types of interventions are now being pursued in the U.S. to ameliorate the second of these two structural barriers and increase IDUs’ access to sterile syringes. Several states and municipalities are engaged in *policy efforts to change existing syringe laws and regulations* to allow increased pharmacy sales of syringes, remove criminal penalties for syringe possession, and include language in laws stating that preventing HIV and other blood-borne pathogens is a “legitimate medical purpose” for prescribing sterile syringes. Many jurisdictions are carrying out efforts to sustain and expand *syringe exchange programs*, which provide IDUs with free sterile syringes and a way to safely dispose of blood-contaminated used syringes. *Initiatives with pharmacists* also are underway to provide education about the role of sterile syringes in reducing the transmission of blood-borne pathogens, address pharmacist concerns and questions about syringe sales and disposal, and encourage changes in pharmacy policy and practice.

All of these interventions are closely interrelated and the success of one partly depends on the success of the others. The effectiveness of interventions that encourage pharmacists to sell syringes to IDUs, for example, is enhanced when laws and regulations that limit pharmacy sale of syringes and that prohibit possession of syringes are repealed. Similarly, for IDUs to openly participate in syringe exchange programs, the public health implications of laws that make possession of syringes a crime should be reviewed. An individual IDU makes

approximately 1,000 injections each year, which even in a moderate-size city adds up to millions of injections a year (Lurie et al., 1998). Therefore, achieving the recommendation of the one-time-only use of sterile syringes will require the coordination of all of these interventions so that IDUs who continue to inject will be able to obtain and safely dispose of a sufficient number of sterile syringes to prevent the acquisition or transmission of blood-borne pathogens.

The magnitude of this challenge to adequate coverage is illustrated by Montreal, a city that has made major strides in ensuring that IDUs can obtain sterile syringes (it does not prohibit the sales of syringes without prescription, it encourages pharmacy sales, and it has active and well-supported syringe exchange programs). An analysis estimated that in 1994 Montreal’s 10,000 IDUs injected 10,683,000 times (Remis et al., 1998). About 338,000 sterile syringes were distributed through pharmacy sales and syringe exchange programs. This meant that only 3.2 percent of the need for sterile syringes was being met. Based on these results, the Montreal Regional Public Health Department removed the quota of 15 syringes that could be exchanged at one time and drafted an action plan to expand the number of sites for syringe distribution through community organizations, health centers, and pharmacies, with a target of more than 1 million syringes distributed by 1997. In 1996, 500,000 syringes were distributed. Though this represented significant progress, the number distributed in 1996 was still far short of the number of sterile syringes needed.

In October 1999, the American Medical Association (AMA), the American Pharmaceutical Association (APhA), the Association of State and Territorial Health Officials (ASTHO), the National Association of Boards of Pharmacy (NABP),

<sup>1</sup>This includes the U.S. Public Health Service, the Institute of Medicine of the National Academy of Sciences, and the U.S. Prevention Services Task Force.

and the National Alliance of State and Territorial AIDS Directors (NASTAD) issued a joint letter urging state leaders in medicine, pharmacy, and public health to coordinate action to improve IDUs' access to sterile syringes through pharmacy sales. They encouraged public health leaders to work to reduce state-level legal and regulatory barriers that restrict access, expand availability of substance abuse treatment, and improve options for safe disposal of syringes (NASTAD, 1999). This statement builds on previous similar policies adopted by the APhA in 1999, the AMA and NASTAD in 1997, and ASTHO in 1995.

#### POLICY EFFORTS TO INCREASE IDUS' ACCESS TO STERILE SYRINGES

As described above, most states prohibit IDUs from possessing or carrying sterile syringes and many states bar their sale without a valid medical prescription. The result of these restrictions is that even if IDUs are legally able to acquire sterile syringes, they often do not want to carry and are unable to safely dispose of them because of the potential for arrest and criminal prosecution (Bluthenthal, Kral et al., 1999; Bluthenthal, Lorvick et al., 1999; Koester, 1994; Springer et al., 1999). This environment serves to increase transmission risk because IDUs who are concerned about being arrested for obtaining or carrying syringes are more likely than other IDUs to share syringes and injection supplies (Bluthenthal, Kral et al., 1999; Bluthenthal, Lorvick et al., 1999).

Although widespread negative opinions of drug users and a reluctance to appear supportive of drug use make it difficult to change syringe laws and regulations, several states have done so. In 1992, Connecticut partially repealed its laws and regulations that limited pharmacy sales of syringes and made possession of syringes a crime. This allowed pharmacy sales of up to 10 syringes without a prescription and legalized the possession of up to 10 clean syringes

(Groseclose et al., 1995; Valleroy et al., 1995). In 1993, Maine changed its laws so as to allow anyone aged 18 or older to purchase from a pharmacy any quantity of syringes (Beckett et al., 1998). In January 1997, the Maine state legislature adopted rules to permit legal syringe exchange and to remove the criminal penalties for possessing 10 or fewer syringes. Other states have tried other approaches. For example, some state legislatures have given health departments the power to establish SEPs and to exempt them from drug paraphernalia and syringe prescription statutes. Five states (Hawaii, Maryland, Massachusetts, New York, and Rhode Island) and the District of Columbia have carved out an exemption in their drug paraphernalia laws for SEP staff and participants. Three states have specifically exempted SEPs from their prescription laws (Connecticut, Massachusetts, Rhode Island). In California, legislation went into effect in January 2000 that permits the use of public funds for SEPs after a local agency has declared a health emergency for hepatitis C and AIDS. However, the city or county must renew the state of emergency every 14 days to keep the new law in effect. New legislation exempts cities and public employees from criminal prosecution if the SEP is operating under a declared public health emergency.

Results from states that have changed their laws have been positive. For example, after Connecticut partially repealed its syringe laws, most pharmacies in the state (about 87 percent) began to sell nonprescription syringes, though in limited numbers (Valleroy et al., 1995; Wright-De Agüero et al., 1998). As a result, fewer IDUs bought syringes on the street, syringe sharing decreased, and police reported fewer needlestick injuries (Groseclose et al., 1995).

Those in Maine who worked for successful policy changes to improve access to sterile syringes attribute their success to the following actions, which were focused on building an environment of collaboration and a sense of common purpose among the

various stakeholders (Beckett et al., 1998):

- surveying pharmacies to identify current syringe sale policies, practices and barriers;
- building coalitions to work for legislative action to modify or repeal criminal penalties for possession of syringes; and
- conducting conferences and other awareness-building events among a wide variety of interest groups (pharmacists, substance abuse specialists, law enforcement officers, legislators, HIV prevention providers, drug users, and advocates of drug users) to discuss relevant issues and necessary action steps.

#### SYRINGE EXCHANGE PROGRAMS

Syringe exchange programs (SEPs) are a second important strategy for increasing IDUs' access to sterile syringes. SEPs allow IDUs to exchange their used needles and syringes for new, sterile injection equipment at no cost. By collecting used injection equipment, SEPs remove blood-contaminated syringes from circulation and allow for safe disposal of equipment that may have been contaminated with HIV or hepatitis. SEPs were first introduced in the United States in the late 1980s. By 1997, there were 123 programs in 33 states, the District of Columbia, Puerto Rico and Guam (CDC, 1998a). These programs exchanged over 17 million syringes in 1997, but two-thirds of these were exchanged by the 10 largest programs. One-half of the SEPs distribute fewer than 50,000 per program per year. SEPs in the U.S. are able to cover only a small percentage of the need for sterile syringes.

IDUs are drawn to SEPs because they get free syringes. This "passive outreach" strategy has an added benefit because it gives programs an efficient way to reach IDUs with additional services and interventions. These services include HIV/AIDS education and counseling; condom distribution to prevent sexual transmission of HIV;

primary medical services; referrals to substance abuse treatment and other medical and social services; bleach distribution for disinfecting injection equipment; distribution of alcohol swabs to help prevent abscesses and other bacterial infections; on-site HIV testing and counseling; crisis intervention; and screening for tuberculosis, hepatitis B, hepatitis C, and other infections. SEPs vary widely in their locations (fixed versus roving sites), hours of operation, the number of syringes allowed for exchange, and other policies.

Because of the controversy associated with SEPs, a great deal of research has been conducted on their effects and outcomes. This work has shown that SEPs have significant positive effects on preventing adverse health consequences associated with injection drug use and that SEPs do not increase drug use or promote the initiation of injection drug use (Des Jarlais et al., 1996; Hagan et al., 1995; Heimer, 1998; Heimer et al., 1994; Kaplan and Heimer, 1992; Lurie et al., 1993; Vlahov and Junge, 1998; Vlahov et al., 1997; Watters et al., 1994). Other benefits of SEPs are that they can facilitate the entry of IDUs into substance abuse treatment and other services that can reduce the risk of HIV infection (Heimer, 1998). SEPs have also been shown to successfully engage IDUs as peer outreach workers to create new exchangers and increase the number of syringes exchanged (Whiticar and Smetka, 1999).

Results showing higher HIV incidence among IDUs using SEPs in Vancouver (Strathdee et al., 1997) and Montreal (Bruneau et al., 1997) have been interpreted by some to suggest that SEPs may contribute to the spread of HIV. However, investigators in these cities have shown that SEPs are not causally associated with HIV transmission and that this association was confounded by the fact that SEPs attract higher-risk users (Archibald et al., 1996; Schechter et al., 1999). Both Canadian cities have continued to expand their SEP services.

Despite their success, syringe exchange programs face continuing challenges. These include legal and regulatory restrictions, precarious funding, and, in some locations, community opposition. While some communities welcome SEPs, others strenuously reject them. This opposition comes from local leaders, the general public, or residents of the neighborhoods in which they would be located. Some objections relate to beliefs that SEPs will increase drug use among participants and attract youth or new individuals to drug use. Other objections are that SEPs will threaten the safety of the community because they will foster an increase in illicit drug sales in the area and result in people discarding contaminated syringes in the community. However, a recent study examining the potential effect of SEPs on the formation of drug-using social networks found that this was unlikely to occur (Junge et al., 2000).

#### INITIATIVES WITH PHARMACISTS

The Public Health Service recommendation that IDUs who cannot or will not stop injecting should consistently use sterile syringes to prevent transmission of blood-borne infections provides a legitimate medical foundation for the sale of sterile syringes to IDUs. Pharmacies, therefore, can play a crucial role because they are a reliable source of sterile syringes. Pharmacies are conveniently located in most neighborhoods, and often have extended hours of operation. Many are open 24 hours a day. In addition, they are staffed by trained, licensed professionals who are able to provide sound medical advice and to make referrals for a variety of related services, including HIV testing and counseling, substance abuse treatment, health care, and other community services. They also provide a safe environment for IDUs to make their purchases and some degree of anonymity for those IDUs who do not want to self-identify by going to an SEP. Some pharmacies accept used syringes for disposal.

Even in states that have partially or completely repealed laws and regulations banning the sale of sterile syringes, however, sales may be hampered by specific pharmacy store policies restricting the sale of syringes to IDUs, the personal reluctance of individual pharmacy managers or pharmacists to sell syringes to IDUs, or other factors that create barriers to buying syringes. For example, pharmacy practice regulations that require purchasers to show identification, sign a register of syringe purchasers, and confirm that the syringes sale is for a “legitimate” purpose, reduce IDUs’ ability or willingness to come into the pharmacy and buy syringes. These policies and attitudes are partly due to store managers’ and pharmacists’ concerns that IDUs will discard contaminated syringes around their businesses and in the community (Case et al., 1998; Gleghorn et al., 1998; Singer et al., 1998; Wright-De Agüero et al., 1998). Another reason may be the limited amount of training and academic material on addiction and the relationship between injection drug use and blood-borne pathogens provided by schools of pharmacy to their students.

Some states are carrying out interventions with pharmacy managers and pharmacists in conjunction with efforts to repeal restrictive laws and regulations that limit pharmacy sales of syringes. For example, several state health departments are working with state pharmacy associations, medical societies, and boards of pharmacies to raise awareness about the barriers to the purchase of sterile syringes and to review current laws and regulations. In Connecticut, Minnesota, and Maine, where laws prohibiting the purchase or possession of syringes have been partially repealed, partnerships between health departments and pharmacies have been formed, education has been conducted to address pharmacists’ concerns, and pharmacists have been encouraged to sell syringes to IDUs. Results from one peer education program for pharmacists in Connecticut demonstrate that pharmacists can become active participants in AIDS prevention

activities; pharmacies, schools of pharmacy and local health departments can develop collaborative linkages to carry out HIV prevention for IDUs; and professional peer education for pharmacists can be effective in expanding prevention services for IDUs (Weinstein et al., 1998).

Despite this progress, states and organizations face a number of significant challenges as they work with pharmacists to change policies related to selling sterile syringes to IDUs. One important challenge is attitudinal. Pharmacists are trained to distrust IDUs and drug users, who may try to use bogus prescriptions or rob the pharmacy. They may also fear that an increase in sales of syringes to IDUs might attract drug users to the neighborhood and create safety and littering problems.

Sales of sterile syringes also raise issues related to safe disposal of used syringes. Community options for safe disposal of used syringes are often limited. The public worries that IDUs will discard syringes in their neighborhoods without recognizing that diabetics who use insulin contribute a substantial number of used syringes (Macalino et al., 1998). Further, pharmacists may mistakenly equate the pharmacy sale of syringes to IDUs with syringe exchange in the pharmacy.

### **Interventions in the Criminal Justice System**

Because the possession and sale of illicit drugs and syringes are crimes and drug users are often involved in crimes to support their drug addiction, IDUs are frequently arrested or in prison or jail. A recent study on substance abuse and prisoners found that 81 percent of state inmates, 80 percent of federal inmates, and 77 percent of local jail inmates had used an illegal drug regularly; been incarcerated for drug selling or possession, driving under the influence of alcohol (DUI) or another alcohol abuse violation; were under the influence of alcohol or drugs when they committed the

crime for which they were in corrections; committed their offense to get money for drugs; had a history of alcohol abuse, or shared some combination of these characteristics (Belenko, 1998). In 1996, an estimated 250,000 state prison inmates had injected drugs, including 120,000 who had shared needles. Some 14,000 federal prison inmates had injected drugs, including 6,000 who shared needles (Belenko, 1998).

At the same time, inmates in prisons and jails have disproportionately high rates of HIV infection and other STDs, hepatitis, and other health problems. At the end of 1996, 2.3 percent of male and 3.5 percent of female state and federal prison inmates were known to be infected with HIV (Hammett et al., 1999). Confirmed AIDS cases were found in 0.5 percent of all inmates, a rate six times higher than that of the total U.S. population. The high-risk behaviors responsible for the transmission of HIV and other blood-borne illnesses among inmates include high-risk sexual activity, sharing of needles and other drug injection equipment, and tattooing with improvised tools and materials (Calzavara et al., 1997; Dolan et al., 1996; Mahon, 1996; Struckman-Johnson et al., 1996).

Given the large numbers of IDUs involved with the criminal justice system and the large numbers of at-risk and infected individuals, this setting is a crucial venue for HIV- and hepatitis-related interventions and services. Providing a range of health and prevention education interventions to inmates not only benefits them and their overall health, but can improve the health of the communities to which the vast majority of inmates return (Hammett et al., 1999).

Prevention services currently offered to incarcerated populations vary widely across state, county, and city jails and prisons. They include instructor-led and/or peer-led HIV education, pre- and post-test counseling, multi-session prevention counseling, the use of audiovisual materials, and the distribution of printed materials (Hammett et al., 1999).

Risk reduction strategies have not been widely adopted in U.S. correctional systems. For example, only two state prison systems and four city/county jail systems make condoms available to inmates. However, most correctional systems provide HIV antibody testing, although testing policies differ widely. Few systems routinely screen inmates for STDs and only limited viral hepatitis prevention and treatment services are available.

The few systems that provide an integrated continuum of care for at-risk and HIV-infected inmates provide the following services:

- screening and identification of medical and psychosocial problems;
- case management, including the use of a medical treatment plan;
- substance abuse treatment;
- provision of antiretroviral medications and prophylaxis of opportunistic infections;
- mental health services;
- hospice care;
- discharge planning; and
- continuity of care and community linkages when prisoners are released.

Although few HIV prevention programs in correctional settings have been rigorously evaluated, limited evidence suggests that they can be successful in reaching this high-risk population with practical risk-reduction messages (Hammett et al., 1999). For example, several innovative models of prison-based substance abuse treatment programs that use a therapeutic community approach have resulted in reduced rates of return to the correctional system and sustained drug abstinence and condom use at follow-up (Field, 1989; Inciardi, 1996; Wexler et al., 1994). These innovative programs include New York State's Stay'n Out, Oregon's Cornerstones program, and Delaware's Crest Outreach Center program. Jail-based methadone maintenance has shown positive

results among participants, including lower rates of drug use and criminality after release (Magura et al., 1993).

One of the most important types of interventions in prisons and jails is education and prevention efforts led by inmates themselves. These programs can be cost-effective and flexible, and they have an added credibility that programs led by outsiders cannot match. Peer-led programs also provide significant benefits to peer educators themselves. Through participating in the programs, these inmates can develop a positive focus in their lives, regain a sense of purpose and empowerment, and realize that they are able to influence others in ways they never believed possible (Hammett et al., 1999). The careful selection of peer trainers and open support of corrections staff are among the factors contributing to the success of such innovative programs as the peer program at Louisiana State Penitentiary in Angola, the AIDS Counseling and Trust program at Louisiana's Avoyelles Correctional Center, the peer programs in California's state prisons at San Quentin, Frontera, and Vacaville, and the AIDS Video Project and Peer HIV Education Project in the Los Angeles County Juvenile System. Several innovative models of instructor-led HIV/AIDS education and prevention programs also have evolved in correctional systems. These include the Forensic AIDS Project conducted in the San Francisco jails and the Corrections AIDS Prevention Program conducted at Rikers Island in New York City (Hammett et al., 1999).

Although many correctional systems in the U.S. have instituted HIV prevention services, numerous gaps in coverage still exist for IDUs, both for those in the system and those leaving jail or prison to return to their home communities. Gaps for those in the system can be found in insufficient numbers of instructor-led and peer-based HIV education and prevention programs. For all inmates, there is a lack of comprehensive substance abuse treatment and mental health services. Supervised medical care services are

also lacking for HIV-infected IDU inmates. Many HIV seronegative and seropositive inmates leaving the system, including those using antiretroviral drug therapy for HIV infection, still do not receive appropriate discharge planning or continuity of substance abuse treatment and medical services after release. Without planning and support, many ex-prisoners are arrested and jailed again.

These gaps occur for a variety of reasons. A primary reason is financial. HIV prevention and treatment services, particularly treatment services, can be costly and the issue of who should pay has not been adequately addressed. Because inmates are legally wards of the government correctional system, health and substance abuse agencies (for example, Medicaid) do not pay for services inside prisons and jails. At the same time, most correctional systems have limited budgets to address issues related to preventing and treating substance abuse, blood-borne diseases, and mental health issues.

A second major reason relates to differences between the philosophies, perspectives, and priorities of public health and correctional agencies. When these differences are not sensitively addressed, they can make collaboration difficult because they undermine respect by public health staff for the skills and expertise of correctional medical staff and other correctional staff and they promote obstruction and lack of cooperation on the part of correctional staff (Hammett, 1998).

A third challenge facing efforts to reduce HIV and other blood-borne illnesses among IDUs in prisons and jails is the primary need for correctional systems to maintain security and to control inmates. Administrators of correctional systems often do not want to acknowledge that HIV risk behaviors, such as men having sex with men or injection drug use, are occurring in their facilities. Prisoners also may not want to acknowledge these behaviors for fear of sanctions. In addition, specific security measures limit the effectiveness of prevention efforts. For example,

the frequent movement of inmates within and between facilities disrupts the continuity of educational programming, counseling, and care. Requirements that prisoners be escorted by guards to meetings with health and HIV prevention staff may restrict inmates' participation in counseling and education initiatives and significantly threaten confidentiality protections. The prohibition against condom distribution because they are considered contraband closes off a major risk reduction intervention.

Finally, HIV education programs face challenges in working with diverse inmate populations having different cultures, languages, and literacy levels or who may be incarcerated for only a short time.

### **Strategies to Prevent Sexual Transmission**

Sexual transmission of HIV and hepatitis involving IDUs is an important factor in the spread of these diseases in the U.S. In 1999, 13 percent of the new AIDS cases reported that year were among men and women whose sex partners were IDUs. Thirteen percent were among male IDUs who also reported having sex with other men (CDC, 1999a). High-risk sexual behavior is also strongly associated with hepatitis B transmission (CDC, 1999b). High-risk drug behaviors and high-risk sexual behaviors are often linked (Chu et al., 1998). For example, a large portion of IDUs use alcohol and/or crack cocaine, which are often associated with increased frequencies of unsafe sexual behavior (Edlin et al., 1994). Some IDUs support their drug habits by exchanging sex for money or drugs. For these reasons, the extent to which IDUs change their sexual behaviors in response to these diseases is critical. This is particularly true in light of evidence showing that although IDUs will make large changes in their injection risk behavior in response to concerns about AIDS, changes in sexual behavior are generally more modest. All studies that have compared changes in injection risk behavior with changes in sexual risk behavior found

greater changes in injection risk behavior (Friedman et al., 1993). In addition, it appears that IDUs are more likely to change sexual risk behaviors (reduce number of partners, increase use of condoms) with casual sexual partners than with their primary sexual partners (CDC/ACDP, 1999; Friedman et al., 1994; Friedman et al., 1999) or with sexual partners who do not inject illicit drugs (Friedman et al., 1994; Friedman et al., 1999; Vanichseni et al., 1993). The reluctance to use condoms with main partners may be partly due to concerns that such action violates the intimacy and trust developed in the relationship.

Distributing condoms and information have been an important means of helping IDUs reduce their risk of sexual transmission. These materials are given out for free by most outreach workers, syringe exchange and other risk reduction programs, drug users' organizations, and some substance abuse treatment programs. One-on-one sexual risk reduction counseling and group interventions are also conducted by peers to address skills building and rehearsal, interpersonal communication, problem-solving, situational analysis, and self-management strategies. Intervention strategies for female drug users and sexual partners of drug users have stressed the importance of building self-esteem, social supports, and sexual negotiation skills to encourage safer sex practices with partners.

Several approaches to sexual risk reduction interventions have had particularly good results. For example, skills-building interventions that target sexual risk reduction have shown more positive effects in improving drug users sexual risk reduction than have interventions that try to target risk reduction in general (Beardsley et al., 1996; El-Bassel and Schilling, 1992; Schilling et al., 1991). Other interventions that have been effective in sexual risk reduction with drug users have included the AIDS Community Demonstration Projects in five U.S. cities

(CDC/ACDP, 1999), the use of a problem-solving therapy model in a male detention center (Magura et al., 1994), and a condom giveaway program at an outpatient substance abuse treatment program (Calsyn et al., 1992).

In developing strategies to reduce sexual transmission, agencies and organizations should tailor them to specific high-risk groups (for example, in-treatment as well as out-of-treatment drug users) and to specific goals (for example, preventing acquisition of infection in uninfected IDUs and preventing transmission from infected IDUs to others). These strategies should also take into consideration the determinants of sexual transmission, including the consistency of condom use, the presence of concurrent STDs, the presence of concurrent injection drug and crack use, and the extent of sexual activity while high. Interventions designed for the sexual partners of IDUs are an important element of these strategies.

### **HIV Counseling and Testing, Partner Counseling and Referral Services, and Prevention Case Management**

A comprehensive approach to preventing HIV and other blood-borne infections among IDUs must include the capacity to allow individuals to discover whether they are infected, and if they are, to help them inform their partners. If they are not infected but engage in high-risk practices, the approach can also help IDUs begin or sustain behavior changes that will reduce their risk of acquiring or transmitting the infection. Three services are designed to meet these objectives:

- HIV prevention counseling and testing (C&T);
- partner counseling and referral services (PCRS); and
- prevention case management (PCM).

HIV counseling and testing services are generally the first step. The HIV antibody

test results and the person's history of risk behavior and other factors determine whether he or she is referred to the other services. Because these three types of services are client-centered and one-on-one, they have the potential to address the complex lives and circumstances of some IDUs and more effectively influence their risk behaviors than can more limited and diffuse interventions. In addition, these services have the potential to provide the continuity of care that is so important to successful outcomes. Each of these services is discussed in greater detail below.

### **HIV PREVENTION COUNSELING AND TESTING (C&T)**

HIV C&T is a prevention intervention that provides HIV antibody testing and individual, client-centered risk reduction counseling. It provides a private and confidential way for individuals to learn their HIV serostatus and get further help, whatever the results of the testing.

HIV antibody testing is provided to individuals who seek, either through private care providers or publicly funded programs, to determine if they are living with the HIV virus. If the results of the test are positive, they can be referred to clinical care and case management. If the results are negative, they can receive counseling and support for risk reduction efforts and referrals for needed services.

The counseling element, a short-term intervention involving two brief sessions (one before and one after the antibody test), has several functions, including:

- offering information on HIV testing and helping a client make a decision about being tested;
- helping clients understand their responsibility, if their HIV test results are positive, for ensuring that sex and drug-use partners are informed of their possible exposure,

and for referring their partners to HIV prevention counseling, testing, and other support services;

- reviewing all available options for partner counseling and referral services (PCRS);
- helping assess a client's risk of acquiring or transmitting HIV;
- helping clients develop a realistic and incremental plan for reducing their risk; and
- offering referrals to clients for substance abuse treatment or other interventions, such as prevention case management (PCM), for more intensive risk reduction services if needed.

Given that many IDUs mistrust conventional health service systems or are unable to obtain services, agencies and providers must offer C&T services in settings where IDUs are already found (such as substance abuse treatment or criminal justice) and deliver them in ways that are tailored to the specific circumstances of the IDUs who will receive them. For example, in November 1987, the City of Boston's Department of Health and Hospitals, the Division of Drug Rehabilitation of the Massachusetts Department of Public Health, and the Massachusetts Center for Disease Control established Project TRUST (Teaching, Referral, Understanding, Support, and Testing) at Boston City Hospital. The project offered anonymous HIV testing in conjunction with a range of related prevention, education, referral, and social support services. A number of factors helped attract IDUs and increase the numbers of people offered counseling and testing, including the range of free services available without a need for appointments, staff who included recovering IDUs, location in a neighborhood with a visible drug-user presence, and anonymity (CDC, 1989). New, rapid HIV antibody tests are being developed that will allow a person to be tested and receive their results in one visit (CDC, 1998b). This may be attractive to many IDUs, for whom a

second visit to receive results can be difficult to manage. Another possibility that could be used effectively with IDUs is oral fluid testing kits, which allow antibody testing without the need for a blood sample. This permits HIV testing to be carried out in outreach settings, making it much easier to reach a larger number of IDUs with this service.

Research conducted among IDUs and other drug users has shown that HIV C&T has resulted in some beneficial behavior changes, including positive impacts on both drug-related and sexual practices (Gibson et al., 1999). As with general at-risk populations, C&T has produced a more positive effect with HIV-infected drug users than with HIV-negative or untested IDUs (Weinhardt et al., 1999; Wolitski et al., 1997). Studies with general at-risk populations and IDUs have shown that both standard, 2-session and enhanced, 4-session counseling interventions significantly increased participants' condom use (Kamb et al., 1998). Compared to standard interventions, enhanced HIV C&T has had a greater effect on IDUs' needle risk behaviors (Siegal et al., 1995) than on their sexual risk behaviors (McCusker et al., 1993).

A number of challenges limit the potential impact and benefits of counseling and testing services. Perhaps the most important issue is that C&T is a short-term intervention and therefore would be expected to have a relatively limited impact on risk behaviors. Individuals frequently go through a relatively long cognitive and behavioral process, including several cycles of attempted change and relapse, before achieving lasting behavioral change (Prochaska, 1989). In many cases, individuals must come to a testing site twice, once to have the test performed and once to receive their results a week later. Many persons who are tested do not return to receive their HIV antibody test results, especially those who are tested in STD clinics. Further, some individuals who test positive have difficulty being integrated into more intensive services, such as

HIV medical care, case management, and support services. Finally, and most important for IDUs, publicly funded HIV C&T does not now include counseling, testing, and treatment for other blood-borne infections that have a significant impact on IDUs, particularly viral hepatitis.

## PARTNER COUNSELING AND REFERRAL SERVICES (PCRS)

PCRS, also known as partner notification, is a public health activity that evolved from "contact tracing" activities developed earlier in the 20th century for the control of sexually transmitted diseases, particularly syphilis. Public health workers conduct confidential interviews with newly identified infected persons to find out the names of and tracing information for recent sexual or drug contacts who are at high risk of also being infected and to make confidential efforts to locate them, recruit them for diagnostic tests, and provide treatment as needed (Bayer and Toomey, 1992; Cates and Toomey, 1990).

PCRS can have important benefits for individual IDUs and their communities. PCRS provides an opportunity for agencies to notify the sexual and drug-use partners of infected individuals of their exposure to HIV and, potentially to viral hepatitis also, to counsel them, and potentially to offer longer-term follow-up. If already infected, the partners' prognosis can be improved through earlier diagnosis and treatment. If not infected, the partners can be assisted in changing their risk behavior, thus reducing the likelihood of acquiring the virus. From an epidemiological standpoint, following the chain of transmission from one HIV-infected individual to another within and across social networks permits public health investigators to chart the course of the epidemic and conduct more effective prevention planning. Epidemiologists suspect that recently infected persons account for a substantial proportion of transmission,

either because they have higher viral loads than those who have been infected longer and are therefore more infectious, or because they have more sex partners, or both (West and Stark, 1997). Identifying and treating infected partners early may reduce HIV transmission by reducing the number of potentially infectious contacts (Fenton and Peterman, 1997).

PCRS also can yield important evaluation information for HIV prevention programs. If conducted in conjunction with social network methods, it can aid in identifying networks with priority prevention and treatment needs and insight on how to access them. In addition, partners can be interviewed about their past experience with previously used prevention services and the effectiveness of those services in helping them reduce risk.

PCRS begins when an IDU seeks HIV prevention C&T. If the HIV test is positive, he or she is given the opportunity to receive PCRS at the earliest appropriate time. During the initial PCRS interview, the counselor will discuss with the client his or her responsibilities to sexual and drug-use partners and available options for notifying them of the client's infection status. The HIV-infected client is encouraged to voluntarily and confidentially disclose the identifying, locating, and exposure information for each partner. The PCRS provider and client together formulate a plan and set priorities for notifying partners. Partner referral options include:

- **client referral** in which the HIV-infected person agrees to personally inform partners about possible exposure and refer them to services;
- **provider referral** in which the provider, usually health department staff, with the consent of the client, takes responsibility for contacting/referring partners;
- **dual-referral** in which the HIV-infected person informs the partner of his/her HIV infection in the presence of the provider; and

- **contract-referral** in which the provider informs the partner only if the client does not notify the partner within a negotiated time period.

During the notification process each partner is:

- informed of possible exposure to HIV and other STDs or blood-borne pathogens;
- provided with accurate information about HIV transmission and prevention;
- informed of the benefits of knowing one's serostatus;
- assisted in obtaining counseling, testing, and other support services; and
- cautioned about the possible negative consequences of revealing their own or others' serostatus to anyone else.

Many HIV-infected drug users are critical of partner referral interventions experienced in the past (Rogers et al., 1998). These opinions are based on a mistrust of government agency involvement and concerns about confidentiality and potential discrimination in disclosing information related to their behaviors and their partners. However, the few studies on HIV partner referral with drug users provide some insights into the kind of intervention that may work best with them (Levy and Fox, 1998; Rogers et al., 1998). One innovative approach to partner referral with drug users builds on the success of community outreach methods by adding contact tracing and partner referral to the role of outreach staff. With the understanding that IDUs often can be more readily reached using community-based indigenous staff members, the Outreach-Assisted Model of Partner Referral uses indigenous outreach workers in a more active role delivering street-based HIV counseling, testing, and partner referral (Levy and Fox, 1998). The expanded outreach model offers testing to IDUs in an environment that is more comfortable and community oriented than those IDUs generally experience in using public health HIV testing services.

To date, no research has been conducted on the effectiveness of partner notification in helping partners adopt safer behaviors or preventing new infections. Research has focused on the process and its effectiveness in reaching partners, testing them, and identifying seropositivity rates (Macke et al., 1999). Most HIV-infected individuals who take part in HIV C&T willingly participate in PCRS (West and Stark, 1997), although the rates of participation have been found to vary considerably across existing state programs (Crystal et al., 1990; Landis et al., 1992; Pavia et al., 1993; Spencer et al., 1993; Wykoff et al., 1991). One study, conducted with IDUs in Utah, showed a participation rate of 93 percent (Pavia et al., 1993). Further research is needed to improve partner notification procedures and tailor them to specific populations, to understand the impact of new testing technologies on partner notification, and to understand the consequences of partner notification for individuals and their partners (Macke et al., 1999).

HIV-infected individuals who take part in PCRS name approximately three partners, although this has also varied considerably across state programs. Of the partners named, the majority are sex rather than drug-use partners. Of those partners named, state program records indicate that 60 to 80 percent are located (Crystal et al., 1990; Landis et al., 1992; Pavia et al., 1993; Spencer et al., 1993; Wykoff et al., 1991). Provider referral has resulted in the notification of more partners than has patient referral (Jones et al., 1990; Landis et al., 1992). Those index clients with the most past sex partners are least likely to attempt to notify any partner (Marks et al., 1992). If located, sex partners are generally receptive to confidential notification of their potential exposure to HIV by the client or the health department and usually seek HIV testing (West and Stark, 1997).

PCRS also has been effective in uncovering previously undiagnosed HIV infections. IDU partners who are tested have shown

higher rates of HIV infection than have partners with other known routes of transmission (Waldron et al., 1995).

Partner referral faces several challenges, particularly when agencies attempt to find partners of IDUs. One reason is that the success of partner referral depends heavily on the disclosure of names of contacts by the HIV-infected client. IDUs may be particularly unwilling to reveal the names of or other information about partners partially because the drug culture discourages revealing information about others. Other barriers to disclosure can include fear of losing a partner, of losing support and, especially for women, fear of violence (North and Rothenberg, 1993; Norwood, 1995; Rothenberg et al., 1995). However, studies have found that when an infected individual reveals his or her infection to a main partner, the disclosure does not result in separation or disruption of the relationship (Nabais et al., 1996; Padian et al., 1993).

Even when a client discloses drug-use partners' names, it is often difficult to locate these IDUs because the client may know them only by a nickname or street name (Rogers et al., 1998). The long incubation period of HIV and anonymous partners of clients are other reasons why it may be difficult to locate IDU partners.

Because PCRS activities often require the notification of many partners, they can be labor intensive and costly. The cost to counsel and refer one sex partner to needed services ranges from \$100 to \$2,260 and from \$810 to \$3,205 to identify one HIV-infected partner through provider referral (Pavia et al., 1993; Peterman et al., 1996).

Although partner notification for STDs is generally regarded as ethically acceptable, ethical concerns about the role of HIV partner notification as a prevention strategy have been voiced (Fenton and Peterman, 1997). Community representatives often perceive HIV PCRS to be an intrusive activity that is unlikely to protect the confidentiality of the HIV-infected person or

his or her partners (West and Stark, 1997). Health departments are often viewed with suspicion, and their ability to keep personally identifying information confidential is frequently questioned. Efforts are needed to ensure that community HIV prevention needs are met, misconceptions about PCRS practices and policies are corrected, and legitimate concerns about confidentiality and discrimination are addressed.

### PREVENTION CASE MANAGEMENT (PCM)

PCM is an intensive, ongoing, client-centered HIV prevention activity with the fundamental goal of helping individuals with complex lives and circumstances adopt and maintain HIV risk-reduction behaviors. For those who are living with HIV, prevention case management helps in obtaining and adhering to treatment for HIV. It provides counseling, support, and service assistance to address the relationship between HIV risk and other issues such as substance abuse, STDs, mental health problems, and social and cultural factors. PCM staff closely collaborate with Ryan White CARE Act case managers to provide information and referrals for secondary prevention needs of persons living with HIV or AIDS. PCM is also useful for HIV seronegative persons, or those of unknown HIV serostatus who are either engaging in high-risk behavior within communities with moderate to high seroprevalence rates of HIV infection or are otherwise at heightened risk of infection.

Because it has the potential to address a wide range of social problems for persons with multiple and complex HIV risk-reduction situations, PCM is particularly suited for individuals like IDUs, who have or are likely to have difficulty initiating or sustaining practices that reduce or prevent HIV transmission and acquisition. PCM strives to develop an ongoing relationship with each client to provide an environment of trust and understanding within which prevention counseling can take place.

PCM includes the following seven components:

- client recruitment and engagement;
- screening and comprehensive assessment of HIV and STD risks, medical and psychosocial service needs, including STD evaluation and treatment, and participation in substance abuse treatment;
- development of a client-centered prevention plan;
- HIV risk-reduction counseling over multiple sessions;
- active coordination of services with follow-up;
- monitoring and reassessment of clients' needs, risks, and progress; and
- discharge from PCM when the client attains and maintains his or her risk-reduction goals.

Case management is often offered as part of a larger care system and this makes it difficult to assess its effects apart from other services. In particular, it has been difficult to assess prevention case management with HIV seronegative drug users and determine the most effective approaches to use with IDUs because of the high drop-out rate of participants even when the required number of sessions with a prevention case manager is reduced (Falck et al., 1994). Other difficulties in evaluating PCM have been small sample size; the lack of ability to control for disease progression, which can cause a decrease in sexual activity; the failure to collect behavioral data in the time between HIV testing and the first case management appointment; and the failure to collect data on the serostatus of program participants' partners.

At present, five CDC-funded demonstration projects are being carried out to test the effectiveness of PCM on reducing the transmission of HIV from HIV-infected persons. One intervention in California is being conducted within early intervention

program (EIP) sites and employs a risk reduction specialist who uses behavior change theory in the context of client-centered counseling and/or short-term, solution-focused counseling techniques.

Another challenge for PCM services is their greater cost compared to other HIV prevention activities, which can employ peers or paraprofessionals to reach larger numbers of people with less time-intensive, staff-intensive risk reduction strategies.

### **Coordinated Services for IDUs Living with HIV/AIDS**

Because HIV disease is a complex chronic condition, infected IDUs and their families require a changing array of services in their homes, in the hospital or health care facility, and in the community (Keenan, 1990). In addition, anti-HIV medication regimens involve multiple medications with differing schedules and requirements. Failure to follow recommendations can lead the virus to develop resistance to anti-HIV medications. However, with appropriate and high-quality services and medications, IDUs living with HIV can lead healthy, productive lives.

Many IDUs continue to engage in high-risk behaviors after they learn they are infected with HIV and, thus, place others at risk of HIV infection and themselves at risk for collateral health problems (CDC, 1996; HRSA, 1994; Kwiatkowski and Booth, 1998; Metsch et al., 1998). When HIV-infected IDUs are actively engaged in health care, however, they can be followed to identify renewed high-risk sex or drug use and counseled about the effects of these behaviors on themselves and others. HIV-infected drug users who are in substance abuse treatment and are receiving other health services are more likely to comply with HIV/AIDS drug treatment regimens and to reduce their sex and drug risk-related behaviors (Booth et al., 1999).

IDUs living with HIV/AIDS need a full complement of services, delivered in a setting geared to attract IDUs from the community

and retain them. Case managers and prevention case managers need training in issues specific to IDUs, which should help them offer risk reduction counseling and prevention services to these individuals and assist them with managing their chronic and acute health care needs, including taking anti-HIV medication and opportunistic infection prophylaxis as recommended. In addition, a full range of complementary affordable and accessible services should be made available, including substance abuse treatment services, mental health services and assistance with other basic needs such as food, housing, childcare, and job training.

A major barrier to providing comprehensive services for HIV-infected IDUs is inadequate funding. HIV-infected IDUs have high levels of need that are only partially being addressed by the current service system (HRSA, 1994). While acute medical services are generally accessible, other health services (dental, home care, hospice, long-term residential drug treatment) and ancillary services (shelter, food, stable living conditions, vocational training, long-term therapy) often are not adequately provided.

As a marginalized population, IDUs can be less connected to the AIDS-related service delivery system than are other infected individuals. For example, HIV-infected IDUs, including those recently incarcerated, without clinical disease who have less contact with health care providers, have not been receiving optimal care (Celentano et al., 1998). Like non-IDU consumers, many IDUs do not know where to go to obtain services or what services are appropriate for different people at different stages of the disease. The service delivery system is too complex and fragmented for them to navigate and often too remote geographically, socially, and culturally. Some programs prohibit services to active drug users and those who are HIV-infected and this presents formidable barriers for IDUs. Negative attitudes by staff toward IDUs' behaviors and life circumstances exacerbate the situation.

Women living with HIV disease face particular educational, cultural, economic, psychological, physical, and social barriers in accessing and using care (Weissman et al., 1995; Weissman and Brown, 1995). Most are either active or recovering injection drug or crack users who have a history of sexual/physical abuse, psychological distress and depression, and lack of social support. Increased funding for services will help to address these barriers, but other changes are also needed, including:

- expanded outreach to women with HIV;
- changes in substance abuse treatment policies and procedures that do not favor women (for example, those that do not adequately address issues of pregnant women and women with children);
- efforts to build peer networks and ongoing support structures;
- improvements in HIV counseling and testing procedures to ensure that women understand the testing and services needed;
- cross-training of providers in women's issues; and
- enhanced advocacy for women living with drug abuse and HIV disease (Weissman and Brown, 1995).

### **Primary Drug Prevention**

Primary drug prevention is a centrally important strategy in a comprehensive approach to preventing blood-borne diseases among IDUs and reducing the spread to others. By helping individuals avoid drug use and drug injection altogether, these programs help to eliminate the risk of injection-related blood-borne virus transmission. Primary drug prevention programs, which are conducted in a variety of settings, including schools, families, and community-based organizations and through a variety of channels, such as the media, are largely aimed at youth to encourage them to avoid or delay the first use of alcohol, tobacco, marijuana, inhalants, and other drugs. Avoiding or delaying substance abuse can

help youth prevent many problems associated with it, including truancy, academic failure, violence, thefts, motor vehicle crashes, homicides, injuries, suicides, and risky sexual behaviors (Ary et al., 1999; Berger and Levin, 1993; Cohen et al., 1997; Donovan et al., 1988; Farrell et al., 1992; Osgood et al., 1988).

Research has identified effective primary prevention programs that target all forms of substance abuse and reach all populations (Drug Strategies, 1999; NIDA, 1997; ONDCP, 1998). Successful programs incorporate messages and strategies that are tailored to respond to the specific nature of drug use in the community and the level of risk in the audience. In addition, they are age-specific, developmentally appropriate, and culturally sensitive.

Successful programs also are designed to enhance “protective factors” and reduce “risk factors” by:

- raising awareness of external pressures, such as peer pressure and media effects, and internal pressures, such as group identity;

- developing personal social and refusal skills;
- teaching that drug use is not the norm among young people;
- promoting bonding to schools and to constructive role models; and
- using interactive methods of delivery.

Successful primary prevention programs also include a variety of components and characteristics, such as:

- media campaigns;
- consistent anti-drug messages across components and settings;
- environmental and policy initiatives, such as raising the minimum age to buy alcohol;
- a parent/caregivers component;
- training and support to ensure that interventions are delivered as intended; and
- “booster sessions” over the long term to reinforce original prevention goals.

Although primary drug prevention has been shown to have clear benefits — many professionals feel that the primary prevention

movement within communities has been instrumental in reducing regular drug use among adolescents and young adults by two-thirds between 1979 and 1992 (Rusche, personal communication, September 3, 1999) — there are still some limitations that must be addressed. Many of the tested primary drug prevention programs are school-based and their effectiveness with out-of-school youth, who may be at higher risk, is not clear. Some school-based programs whose effectiveness has not been conclusively demonstrated continue to be popular. Furthermore, school-based interventions have been designed and tested mainly with middle school students; programming for younger students and older teens is limited. Progress in evaluation research in this area has also been hampered by methodological limitations, such as limited curriculum assessment that does not consider the multiple requirements teachers must address in the classroom, and a paucity of medium- and long-term follow-up studies of interventions.

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# Appendix B

## Index of Articles and Reports Cited in Appendix A, Organized by Comprehensive Approach Strategy

Author	Substance Abuse Treatment	Community Outreach	Access to Sterile Syringes	Criminal Justice System Interventions	Sexual Transmission	C&T, PCRS, PCM	Services for IDUs Living with HIV/AIDS	Primary Drug Prevention
Abdul-Quader et al., 1987	●							
AED, 1999		●						
AED, 1997	●							
Anderson et al., 1996		●						
Anderson et al., 1998		●						
Anglin et al., 1989	●							
APA, 1996		●						
Archibald et al., 1996			●					
Ary et al., 1999								●
Avins et al., 1997	●							
Ball et al., 1988	●							
Battjes et al., 1991	●							
Bayer and Toomey, 1992						●		
Beardsley et al., 1996					●			
Beckett et al., 1998			●					
Belenko, 1998				●				
Berger and Levin, 1993								●
Blix and Gronbladh, 1991	●							
Bluthenthal, Kral et al., 1999			●					
Bluthenthal, Lorvick et al., 1999			●					
Booth et al., 1999							●	
Booth et al., 1996	●							
Broadhead et al., 1998		●						

Author	Substance Abuse Treatment	Community Outreach	Access to Sterile Syringes	Criminal Justice System Interventions	Sexual Transmission	C&T, PCRS, PCM	Services for IDUs Living with HIV/AIDS	Primary Drug Prevention
Brown et al., 1988	●							
Bruneau et al., 1997			●					
Calsyn et al., 1992	●				●			
Calzavara et al., 1997				●				
Caplehorn and Ross, 1995	●							
Carlson and Needle, 1989		●						
Case et al., 1998			●					
Cates and Toomey, 1990						●		
CDC, 1999a					●			
CDC, 1999b					●			
CDC, 1998a			●					
CDC, 19998b						●		
CDC, 1996							●	
CDC, 1989						●		
CDC, 1984	●							
CDC/ACDP, 1999		●			●			
Celentano et al., 1998							●	
Chu et al., 1998					●			
Cohen et al., 1997								●
Cottler et al., 1998		●						
Coyle et al., 1998		●						
Crystal et al., 1990						●		
DeLeon, 1984	●							
Des Jarlais et al., 1985			●					
Des Jarlais et al., 1996			●					
Dolan et al., 1996				●				

Author	Substance Abuse Treatment	Community Outreach	Access to Sterile Syringes	Criminal Justice System Interventions	Sexual Transmission	C&T, PCRS, PCM	Services for IDUs Living with HIV/AIDS	Primary Drug Prevention
Donovan et al., 1988								●
Drug Strategies, 1999								●
Edlin et al., 1994					●			
El-Bassel and Schilling, 1992	●				●			
Epstein and Gfroerer, 1998	●							
Falck et al., 1994						●		
Farrell et al., 1992								●
Fenton and Peterman, 1997						●		
Field, 1989				●				
Friedman et al., 1999					●			
Friedman et al., 1994					●			
Friedman et al., 1993		●			●			
Friedman et al., 1995	●							
Gerstein and Harwood, 1990	●							
Gibson et al., 1999						●		
Gleghorn et al., 1998			●					
Gleghorn et al., 1995			●					
Gostin, 1998			●					
Groseclose et al., 1995			●					
Hagan et al., 1995			●					
Hahn et al., 1989	●							
Hammett, 1998				●				
Hammett et al., 1999				●				

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Hartel and Schoenbaum, 1998	●							
Haverkos, 1998	●							
Heimer, 1998			●					
Heimer et al., 1994			●					
HRSA, 1994							●	
Hubbard et al., 1989	●							
Inciardi, 1996				●				
Jones et al., 1990						●		
Jose et al., 1996		●						
Junge et al., 2000			●					
Kamb et al., 1998						●		
Kaplan and Heimer, 1992			●					
Keenan, 1990							●	
Koester, 1994			●					
Kwiatkowski and Booth, 1998							●	
Landis et al., 1992						●		
Latkin et al., 1998		●						
Levy and Fox, 1998						●		
Lurie et al., 1998			●					
Lurie et al., 1993			●					
Macalino et al., 1998			●					
Macke et al., 1999						●		
Magura et al., 1994					●			
Magura et al., 1993				●				
Mahon, 1996				●				

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Malow et al., 1994	●							
Marks et al., 1992						●		
McCusker et al., 1992	●							
McCusker et al., 1993						●		
McLellan et al., 1994	●							
Meandzija et al., 1994	●							
Metsch et al., 1998							●	
Metzger et al., 1998	●							
Metzger et al., 1993	●							
Moos, 1974	●							
Moos et al., 1990	●							
Moss et al., 1994	●							
Nabais et al., 1996						●		
NASTAD, 1999			●					
Neaigus, 1998		●						
NIDA, 1999	●							
NIDA, 1997								●
NIH, 1997	●							
North and Rothenberg, 1993						●		
Norwood, 1995						●		
Novick et al., 1990	●							
O'Brien and McLellan, 1996	●							
ONDCP, 1998								●
Orr et al., 1996	●							
Osgood et al., 1988								●
Padian et al., 1993						●		

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Pavia et al., 1993						●		
Peterman et al., 1996						●		
Pickens et al., 1991	●							
Prochaska, 1989						●		
Remis et al., 1998			●					
Rogers et al., 1998						●		
Rothenberg et al., 1995						●		
Schechter et al., 1999			●					
Schilling et al., 1991					●			
Semaan et al., 1998		●						
Serpelloni et al., 1994	●							
Shoptaw et al., 1997	●							
Siegal et al., 1995						●		
Simpson and Savage, 1980	●							
Singer et al., 1998			●					
Spencer et al., 1993						●		
Springer et al., 1999			●					
Strathdee et al., 1997			●					
Strain et al., 1999	●							
Struckman-Johnson et al., 1996				●				
Sufian et al., 1991		●						
Sumartojo et al., 1997		●						
Valleroy et al., 1995			●					

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Vanishseni et al., 1993					●			
Vlahov and Junge, 1998			●					
Vlahov et al., 1997			●					
Waldron et al., 1995						●		
Watters et al., 1994			●					
Weinhardt et al., 1999						●		
Weinstein et al., 1998			●					
Weissman and Brown, 1995							●	
Weissman et al., 1995							●	
West and Stark, 1997						●		
Wexler et al., 1994				●				
Whiticar and Smetka, 1999			●					
Wiebel et al., 1996		●						
Williams et al., 1992	●							
Wolitski et al., 1997						●		
Wriah-De Agüero et al., 1998			●					
Wykoff et al., 1991						●		